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The Governor's Committee on ALZHEIMER'S DISEASE

Final Report



Michael S. Dukakis
Governor

Richard H. Rowland, Ph.D.
Executive Office of Elder Affairs

Lewis H. Weinstein
Committee Chairman

The Commonwealth of Massachusetts

1985

Report of the Governor's Special Committee
on
Alzheimer's Disease

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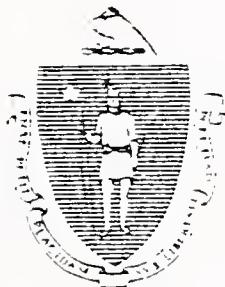


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THE GOVERNOR'S COMMITTEE ON
ALZHEIMER'S DISEASE

FINAL REPORT



Sheila Clemon-Karp, Ph.D.
Staff Director

Lewis H. Weinstein
Committee Chair

THE COMMONWEALTH OF MASSACHUSETTS
1985

Richard H. Rowland, Ph.D.
Secretary, Executive Office
of Elder Affairs

Michael S. Dukakis
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TABLE OF CONTENTS

	<u>Page</u>
Table of Contents	iii
Governor's Special Committee on Alzheimer's Disease Membership.....	iv
Foreword	1
Introduction	8
Recommendations	10
Potential Demonstration Programs	14

Subcommittee Reports

Report of the Family Subcommittee	16
Report of the Community-Based Services Subcommittee	32
Report of the Institutional Care Subcommittee	44
Report of the Current Programs Subcommittee	52
Report of the Education Subcommittee	63
Report of the Research and Practice Subcommittee	69
Report of the Legal Services Subcommittee	75
Report of the Insurance and Finance Subcommittee	85

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FOREWORD

Six months ago, on November 24, 1984, some sixty Massachusetts citizens were sworn in by Governor Michael S. Dukakis, who had appointed them members of the Governor's Committee on Alzheimer's Disease. The Committee had been established by Chapter 5 of the 1984 Resolves of the Legislature. The only charge to the Committee is general: to report "with recommendations for adequate care and support of the victims of this dread disease and their families." The caption is more specific; it states that the Resolve is "Relative to Making a Commitment to the Victims of the Debilitating Disease Known as Alzheimer's Disease, by Providing Respite Care for the Families of These Victims to Assist Them in Keeping These People in Their Own Homes and Avoiding or Postponing the Necessity of Placing Them in Nursing Homes." But the specificity of the caption does not limit the generality of the text of the Resolve. As our Supreme Judicial Court has said: "...[P]lain words in the text of a statute are not to be cut down by its title."

The Committee members constitute an extraordinary cross section of the Massachusetts community concerned with Alzheimer's Disease, individuals from all parts of the Commonwealth. From the Executive Branch came two members of the Governor's Cabinet: The Secretaries of the Executive Offices of Elder Affairs and of Human Services, and five Commissioners. From the Legislature came three Senators and three Representatives. From the medical, scientific and social service communities came leading physicians, teachers, and other experts in psychology, psychiatry, nursing, and social work. Among the members of the Committee were the President, two Vice-Presidents, the Executive Director and 17 other members of "Alzheimer's Disease and Related Disorders Association of Eastern Massachusetts" (ADRDA). The Committee also included a Suffolk County Probate and Family Court Justice, a Vice-President of Blue Cross/Blue Shield, the General Manager of WBZ-TV Channel 4, members of various groups and institutions providing care for Alzheimer's Disease patients and families in their homes, communities and institutions, private, charitable and public, all of them concerned with Alzheimer's patients.

Problems Facing the Committee

Our Committee faced countless problems. Some were obviously unanswerable by us: i.e., the cause of the disease or its cure or respite. No one disagreed with the need for early and correct medical diagnosis, nor with the fact that there was frequent lack of training and knowledge for such diagnosis by local medical practitioners. There were problems galore: the problem of the family not poor enough to obtain Medicaid, but unable to receive even partial reimbursement by Medicare, Blue Cross/Blue Shield, or private insurance; the family frequently spending \$30 to \$40 thousand a year for nursing homes, plus a similar additional amount where private nurses were necessary; the need for respite where an elderly spouse or breadwinner family member spends all non-working time with the Alzheimer's patient and needs some respite or replacement or rest or change

from the day and night support; the problem of the patient without family; the lack of specific numbers as to where Alzheimer's patients are and what care they are receiving; the need for demonstration projects, the need for a better understanding and evaluation of home, community, and institutional care (private, charitable and public); the need to know what other states and countries are doing; and the role of private insurance companies. Our first problem was how to find a way in which 60 individuals could complete in six months an enormous assignment.

Organization

It was clear from the outset that the Alzheimer's Committee, without delegation, could not function effectively as a 60-member Committee. At its first meeting, on December 3, 1984, the Committee decided to create an Executive Board to act between general Committee meetings, and seven Subcommittees: Current Programs, Research and Practice, Education, Finance and Insurance, Families, Community-Based Care and Institutional Care. Later, a Subcommittee on Legal Issues was established. A list of all the Executive Board members, the general Subcommittee Chairperson, and members are included in this report. All Chairpersons and all of the Legislative members were invited to attend Executive Board meetings. Dr. Sheila Clemon-Karp of the Executive Office of Elder Affairs was designated as our Staff Director, together with six members of that Office as staff for our Committee.

Public Hearings

The Committee, at its first meeting, determined to conduct a public hearing in the State House and another in Western Massachusetts; such hearings were held in Boston on February 8, 1985, and at Holyoke Community College two weeks later. Some 70 witnesses testified at the State House during a hearing that began at 10:00 a.m. and, without any break, ended at about 4:30 p.m. In Holyoke there were some 50 witnesses who testified from 10:00 a.m. to about 1:30 p.m. The hearings confirmed the recent statement by Dr. Lewis Thomas, a recognized medical authority, who stated that "Alzheimer's is the disease of this century" and "causes more damage to the family than any disease I can think of." There was overwhelming evidence that "Alzheimer's is an insidious disease; no illness is more terrifying and life altering than Alzheimer's."

The hearings not only raised issues and provided significant testimony, but included poignant reports of family tragedies: some cases of slow deterioration, others of rapid sweeping personality transformation and devastation, uncertainty, bitterness, grief, guilt, anxiety, fright, hopelessness, fixation, groping, particularly when the burden of caring for the patient falls on one individual, usually a spouse, child or sibling, in many cases the family breadwinner. Several witnesses had to cut short their testimony because of their inability to continue to talk; many were in tears.

We also heard from many witnesses of the need for information and education about the disease at all levels. Not only more information and education for the professionals and for the patient and the families, but also for the public generally, including answers to questions: "Who" are

the doctors? "Where are the institutions available to help and their addresses and telephone numbers?" "What kind of care is available?"

Our Committee heard sharp criticism of some physicians and high praise of others. There were repeated reference to "run-arounds", "wrong diagnoses", "no one knows", and above all, not knowing to whom to turn.

The hearings covered the panoramic sweep of the work of all of our Subcommittees; and the testimony, with written statements by the witnesses, became the subject of analysis, discussion and debate and of Subcommittee and Full Committee recommended action. The hearings also brought reports, frequently favorable, occasionally derogatory, about supplementary care in homes, day care centers, community-based agencies and institutions, public, charitable and private; claims of inadequate compensation for care workers and a wide variety of other subjects which concern Alzheimer's patients and their families.

And one question, asked in frustration, was searing. The question was rhetorical: "Why can't our doctors and scientists make a breakthrough for a cause or cure or respite from Alzheimer's? If they were able to discover 'L Dopa' for Parkinson's, why can't they find something that will alleviate Alzheimer's Disease symptoms, that will make life bearable?

Committee and Subcommittee Action

Our Committee concluded early in its existence that it would not recommend state appropriations for medical or medically-related research in view of the grants by the federal government and foundations; that it would recommend appropriations only for home, respite and community-based care, for model or demonstration projects, not only in public institutions, but in private institutions, and for investigation and correlation, as described in the Recommendations in this report.

As each Subcommittee report became available in draft form (and there were several committees with over six draft reports), it was reviewed by the Executive Board, then re-submitted to other Subcommittee Chairpersons and then, as reports approached finality, by other Subcommittee members, until each member of the Full Committee had the opportunity to read all of the Subcommittee reports.

Then came the work of coordinating all the Subcommittee reports, eliminating differences or inconsistencies and grouping together all the recommendations and proposed model (or demonstration) projects. Dr. Marilyn Albert, Assistant Professor of Psychiatry and Neurology at Massachusetts General Hospital and Harvard Medical School, undertook the great responsibility for this assembly, coordination and editing, and several meetings of our Executive Board were devoted to the review and approval of the final documents. Dr. Sheila Clemon-Karp and Dr. Joan Hyde cooperated very effectively in this extensive process. These individuals provided enormous service to our Committee. The final meeting of the Full Committee approved the recommendations and proposals, following some changes, and subject to editing meetings.

Executive Board

The following individuals constitute the Executive Board. Secretary of the Executive Office of Elder Affairs Richard H. Rowland and Secretary of the Executive Office of Human Services Philip W. Johnston, who continuously supported our goals. Dr. Rowland attended our Committee meetings and gave enormous help. Secretary Johnston was unable to come to all meetings but was always represented.

Mrs. Charlotte Alintuck, a Vice-President of Massachusetts ADRDA, was Chairperson of the Subcommittee on Institutional Care. She has a long background in every facet of Alzheimer's Disease and follows the development of federal and state legislation and relevant policies and programs.

Ms. Donna Campbell, Clinical Coordinator for the Dementia Study Unit in the Geriatric Research Education and Clinic Center at the Veterans Administration Hospital in Bedford, whose special nursing unit has won acclaim for the quality of its care.

Warren Dahlin, Executive Director of South Shore Elder Services, served as Chairperson of the Subcommittee on Community-Based Care. He had a full career in the various aspects of home, community, day, and respite care and expertise in long term care.

Dr. Roger Hickler, Geriatrician, with rich experience, is involved daily with the medical care of Alzheimer's patients and with their families' problems: psychological, sociological and economic, as well as medical.

Dr. Robert Morris, Professor Emeritus of the Florence Heller Graduate School of Advanced Studies in Social Welfare at Brandeis University, an authority on health policy for the elderly, with profound wisdom.

Dr. F. Marott Sinex, President of the Massachusetts ADRDA and active at the national level of ADRDA, Microbiologist at the Boston University School of Medicine, an expert in the relationship between Alzheimer's Disease and Downs' Syndrome, with a full background in all the problems of Alzheimer's Disease.

Dr. Richard Tyler, Chief of Neurology at Brigham & Women's Hospital, with great experience in the medical care of dementia patients and the problems of their families.

Dr. Terrie Wetle, Assistant Professor of Health Policy at Harvard Medical School, supervisor of a number of research projects which relate to Alzheimer's patients and families and the cost of medical care.

Subcommittees

In addition to Mrs. Charlotte Alintuck (Institutional Care), Warren Dahlin (Community-Based Care) and Dr. F. Marott Sinex (Current Programs) who were members of the Executive Board; the other Subcommittee Chairpersons were:

Dr. David A. Drachman, Co-Director of the Massachusetts Alzheimer's Disease Center, funded by the National Institute on Aging, and Chief of Neurology at University of Massachusetts Medical School, chaired the Subcommittee on Research and Practice.

Jacob Getson, Vice-President of Massachusetts Blue Cross/Blue Shield, headed the Subcommittee on Finance and Insurance. He had the strong support of his assistant, Dr. Diane S. Piktialis.

Our Education Subcommittee was chaired by Thomas L. Goodgame, General Manager of WBZ-TV Channel 4. In Mr. Goodgame's absence, Dr. Joan Hyde represented and reported for the Subcommittee at Executive Board and General Committee meetings.

Ms. Sonia Boyajian chaired the Subcommittee on Families. Her personal experience enabled her and the many families represented on the Subcommittee to prepare a moving report.

Judge Mary Muse of the Suffolk Probate and Family Court, chaired the Legal Subcommittee. She, Senator Jack Backman, and I selected eight young lawyers and law teachers to assist in preparing a comprehensive report on legal issues.

The Alzheimer's Committee Report

At the meeting of the Executive Board on May 23, 1985, followed by the full Committee meeting, we approved the publication of this report with all the Subcommittee reports, the full Committee's recommendations and proposed demonstration projects, subject to editorial change by Dr. Albert, Dr. Clemon-Karp and me.

While both the Resolve and this report refer to Alzheimer's Disease, what this Committee wrote includes the words: "and Related Disorders." The estimated number of patients with Alzheimer's exceeds the number of those with Related Disorders. Physicians and support groups expressly treat them as one "group" of patients; both have many of the same or similar symptoms and the same end; complete loss of cognitive powers. In addition, many of the problems of victims of Alzheimer's Disease and Related Disorders and their families apply also to those elderly who need long term care.

This report contains a number of recommendations for evaluation and action by the Commonwealth, individuals and agencies.

One group, outside government, the medical and scientific community and the media, but working closely with all of them deserves special commendation. ADRDA gave extraordinary support to the activities of the Committee. We look to ADRDA for continuing advocacy and lobbying, information and educational programs, advice to the public on the needs of Alzheimer's Disease patients and families, and support of research.

Voluntary agencies, such as the constituent and beneficiary agencies of philanthropic organizations, like the United Way, United Community Planning Corporation, Catholic Charities, Combined Jewish Philanthropies, Hebrew Rehabilitation Center for the Aged, and others concerned with the frail

elderly and Alzheimer's patients should be encouraged to form, with ADRDA, an Alzheimer's coalition.

Thanks

As we conclude our current efforts, we owe a debt of gratitude to:

Governor Michael S. Dukakis who showed his confidence in us by our appointment and his continuing interest in our efforts and who only this week assured us that he will give our recommendations and proposals high priority; and to members of his office, including Catherine M. Dunham of Human Resources.

Secretary of the Executive Office of Elder Affairs, Richard H. Rowland and Secretary of the Executive Office of Human Services, Philip W. Johnston for their continuous support and help, personally and through their staffs. Their coordinating efforts, continuing into the future, will play a key role in the Commonwealth's help to Alzheimer's patients and their families.

Special thanks to Dr. Sheila Clemon-Karp of the Executive Office of Elder Affairs, our Staff Director, who was extraordinarily helpful, and to her effective staff: Maureen Barton, Eva Hester, Edward B. Kovar, Andrea Lehtonen, John McGrane, and Julie Tessler.

Our legislative members, Senators George Bachrach, Jack Backman and Edward L. Burke and Representatives A. Joseph DeNucci, Barbara E. Gray and Richard A. Voke, the President of the Senate, William M. Bulger, Speaker of the House of Representatives George Keverian and to all the members of both bodies for their expressed interest in our work, and in anticipation, for their support.

Dr. Marilyn Albert, who graciously undertook the difficult task of coordinating and editing this report, including its recommendations and proposals.

Dr. Joan Hyde for performing a wide variety of important services including coordinating the public hearings and filling in for various chairpersons of Subcommittees.

All the members of the Executive Board and Chairpersons of the Subcommittees, an exceptional collection of experts with a wide variety of talent.

The full Committee, deeply concerned with the problems of Alzheimer's patients and their families, faithful in attending meetings and articulate in expressing their views and devoted to the need to give all possible help through the federal and state governments, and through private sectors.

My secretary and right hand at Foley, Hoag & Eliot, Jean A. Desmond who performed continuously and extensively as secretary and message center.

This report is by no means a final chapter. It is hopefully one step toward the goal of doing all in our power to help Alzheimer's patients and their families.

May 31, 1985

Lewis H. Weinstein
Lewis H. Weinstein, Chairman

INTRODUCTION

In the last decade, Alzheimer's Disease has become a serious societal and medical problem. As our population ages, more and more of us are reaching the age at which Alzheimer's Disease and related disorders reach epidemic proportions.

Although Alzheimer's Disease can strike people as young as 30, its prevalence increases with age, so that less than 1% of the citizens of Massachusetts between the ages of 40 and 60 now suffer from Alzheimer's Disease, 5% to 7% of those aged 60 to 80, and 20% to 30% of the people over 80 have Alzheimer's Disease and other dementing illnesses. Although good diagnosis and records have not been kept, we can estimate, based on epidemiological data, that approximately 40,000 Massachusetts citizens now suffer from Alzheimer's Disease, and another 30,000 from other forms of dementia.

If no cure is found by the year 2000, we project that the total number of Massachusetts citizens suffering from Alzheimer's Disease or a related disorder will exceed 100,000.

Alzheimer's Disease is not only a personal tragedy for those who are stricken and for their families and friends, it is also a very costly disease. It is estimated that half of all Massachusetts nursing home patients have some form of dementia. Neither Medicare nor private health insurance covers the costs of long term care for this or other chronic diseases. The burden of nursing home care alone for Massachusetts patients during 1984, is estimated at \$667,354,000. Twenty-five to thirty percent of this is paid for by individual families at great personal sacrifice, and often impoverishment. The rest is paid for, after the patient becomes indigent, by Medicaid. Under federal law, fifty percent of this is paid for directly out of the coffers of the Massachusetts State government. Total long term care expenditures in Massachusetts for 1984, including chronic hospitals, nursing and rest homes, and home health agencies, are estimated at \$1,026,660,000.

The fact that Alzheimer's Disease touches almost everyone is illustrated by the probability of personal involvement: if both of one's parents survive past 65, there is approximately one chance in three that their child will become responsible for the care of one or the other parent. As the number of elderly reaching age 65 exceeds the number of young people reaching maturity (as it did for the first time in 1984), fewer and fewer working people will be supporting more and more individuals subject to Alzheimer's Disease. These considerations create a time bomb, perilously close to its point of explosion.

Those who have examined the needs of patients and families affected by Alzheimer's Disease in the state of Massachusetts know that there is a need for a more comprehensive and coordinated system of care. Improvements are needed in all of the following areas:

- 1) Provision of information. Families of patients with Alzheimer's Disease need accurate, accessible information regarding the nature

of the disease process, health care professionals who are expert in the diagnosis and management of disease, community facilities that can provide assistance, institutions for those patients who can no longer be cared for at home, and legal and financial guidance.

- 2) Medical expertise. Accurate early diagnosis by physicians expert in the problems of dementia is necessary. Recognition of treatable dementing illness is crucial and highly cost effective. Once the diagnosis is made, there is a great need for continued medical management of problems such as incontinence, concurrent medical illness, and behavior problems.
- 3) Services for patients maintained at home. Respite care, day care, home care, and home health care services are critically needed in adequate quantity to enable families of patients with Alzheimer's Disease to maintain patients at home, and to sustain a reasonable existence for themselves and other members of the family. Legal advice, support groups and a variety of social services are needed as well.
- 4) Institutional care. Because all patients with Alzheimer's Disease who survive long enough eventually require total care, the majority end up in institutions. Adequately financed, insured, subsidized nursing home care is sorely needed for those with advanced dementing illness.

The Governor's Special Committee on Alzheimer's Disease feels that the Commonwealth must become more deeply engaged in a coordinated manner in the provision of solutions to these problems. It is clearly evident that the existing resources and the organization for their efficient utilization are inadequate in Massachusetts and require constructive orderly improvement.

The Committee on Alzheimer's Disease has addressed a broad variety of problems associated with Alzheimer's Disease and related disorders through a review of existing information and the testimony of individuals affected by, or dealing with, Alzheimer's Disease at every level: families of affected patients, health professionals, state officials dealing with public assistance programs, health insurance executives, nursing home managers, etc.

Subcommittees of the Committee on Alzheimer's Disease have reviewed as many facets of the problem as have appeared useful and practicable. As a consequence of these extensive deliberations, the Committee as a whole has derived a number of specific recommendations. Each recommendation addresses one or more of the problems identified above.

We recognize that an effort to deal with the problem of Alzheimer's Disease will be costly, and that there are many state functions that compete for fiscal priority. Nonetheless, we feel that there is an imperative need to come to grips with the problems engendered by Alzheimer's Disease and related disorders. The already existing scope of the problem, and its future rapid expansion, require that an effective, organized, and systematic approach be started at once. To this end we commend the following recommendations:

Budgetary

1. The respite care system of the Executive Office of Elder Affairs should be expanded by 2 million dollars in fiscal year 1986 to provide additional respite care for patients with Alzheimer's Disease and related disorders. The type of respite services available should continue to include: homemaker/personal care, companion, home health aides, skilled nursing, social day care, adult day health, and short term institutional care. Services should continue to be available on a "sliding fee" scale.
2. At least four demonstration programs, funded by Requests For Proposals (RFP), should be developed in the field of dementing illness. Such programs would attempt to provide a more coordinated, systematic, and creative approach toward serving the patients and families who suffer from Alzheimer's Disease and related disorders. Since there is a lack of information about the most effective treatment modalities for these individuals, the demonstrations should explore a number of different models including: health and social service prototypes, institutional and community-related programs, academically and non-academically-related projects. The Long Term Care Work Group (a presently operating inter-agency task force) would oversee the development and evaluation of the demonstration programs and recommend funding (at a cost of no more than \$500,000 per program) for either the Executive Office of Elder Affairs or the Executive Office of Human Services to carry out the actual program planning, funding and evaluation. A staff person from the Office of Alzheimer's Information (see below) would be responsible for working with the Long Term Care Work Group to develop their recommendations.
3. An Office of Alzheimer's Information should be established within the Executive Office of Elder Affairs to oversee the dissemination of information to: the general public, family members, paid and volunteer caregivers, state and government employees, and health professionals. This office would oversee and implement the recommendations of the Special Task Force on Information and Referral for Alzheimer's Disease and related disorders. It would work with the Area Health Education Center (AHEC) to improve the education of health professionals. It would also assist the Long Term Care Work Group in developing and implementing its recommendations related to Alzheimer's Disease and related disorders. The Office of Alzheimer's Information should consist of no less than three staff members, for a total estimated cost of no less than \$85,000 per year.
4. Funds should be appropriated for the Department of Public Health to conduct a health interview survey to determine the number of patients in the Commonwealth with Alzheimer's Disease, their family status, their utilization of resources, and their ability to gain access to the health care system.

5. The Area Health Education Center should receive additional appropriations targeted for the training of health professionals in the area of Alzheimer's Disease and related disorders.
6. The Department of Public Health should be funded to develop education and training material for appropriate in-house and attending staffs of long term care facilities so that they are educated in "state of the art" drug therapy and other management techniques for patients with Alzheimer's Disease and related disorders.

Administrative

1. The Long Term Care Work Group should be directed to develop criteria for at least four demonstration programs in the field of dementing illness. Plans for soliciting, funding, and evaluating the demonstration programs should be provided to the legislature by February 1, 1986. Since the Long Term Care Work Group cannot actually carry out the plans developed by it for the issuance of RFPs or for detailed program planning and evaluation, the responsibility for this should be assigned to the Executive Office of Elder Affairs and the Executive Office of Human Services, as determined by the design of the demonstration programs. The Executive Office of Human Services would be responsible for institutional demonstration programs and the Executive Office of Elder Affairs would be responsible for community-based demonstration programs. Budgetary allocations would be made accordingly. The function of the Long Term Care Work Group should not, however, be limited to overseeing the demonstration programs, but should also include advice and consultation on other issues concerning Alzheimer's patients and their families.
2. A Special Task Force on Information and Referral (I & R) for Alzheimer's Disease and related disorders should be established for one year to evaluate and make recommendations for upgrading existing information and referral services. The activities of the task force should include designing a training program for I & R workers to enhance their ability to provide appropriate information and support. The task force should consist of representatives from existing information and referral systems, both governmental and private. The activities of the task force should be coordinated by the Office of Alzheimer's Information.
3. The Area Health Education Center program should be directed to pursue all appropriate avenues for improving professional education in regard to Alzheimer's Disease and related disorders. This should include: developing new continuing education programs in the area of Alzheimer's Disease and related disorders, encouraging existing programs to include more information concerning Alzheimer's Disease and related disorders, and working with medical schools to expand the training of new physicians in the area of dementing illness.
4. The Executive Office of Elder Affairs is encouraged to continue its efforts to improve the home care system's capabilities to serve the most frail in the community setting, including Alzheimer's patients most in need of services by virtue of their functional impairment.

This capability should include the training of home care staff and the development of new and specialized programs, including home management services (e.g., social workers, occupational therapists, and adaptive equipment) geared to family caregivers of Alzheimer's patients.

5. The purchase of service system in the Commonwealth should be reviewed by the Executive Office of Human Services and the Executive Office of Elder Affairs to insure adequate provision of professional services in community settings. There must be incentives to care for indigent Alzheimer's patients who lack supportive families.
6. There is a need to review and adjust current reimbursement schedules to take into account the special care needs of patients with Alzheimer's Disease and related disorders. Medicaid, Medicare, Blue Cross/Blue Shield, and other insurers, as well as the Rate Setting Commission and the Department of Public Health, should be mandated to work together: 1) to establish an appropriate policy to address this issue with respect to hospitals, nursing homes, adult day health programs and other providers, and 2) to adjust physician's and other provider's reimbursement rates so as to establish appropriate compensation for complex and time-consuming medical services, and avoid financial disincentives for provision of such services.
7. Since the Executive Office of Elder Affairs is mandated to provide service to individuals aged 60 and over, the care of Alzheimer's patients under the age of 60 is frequently neglected. The Executive Office of Human Services, though its Department of Social Services, should organize and provide service to Alzheimer's patients under 60 years of age.
8. The Governor should appoint a commission or committee to deal with legal issues of great concern to patients with Alzheimer's Disease and related disorders, such as: distribution of property and burden of care, trusts, guardianships, conservatorships, durable powers of attorney, living wills, the patient as a research subject, family participation in medical care and the administration of psychotropic medication and the jurisdiction of the Probate and Family Court to deal with these issues.
9. There should be a longer period of retroactive determination of disability for Alzheimer's Disease by the Social Security Administration. This would enable an individual who lost a job due to the impact of the disease prior to diagnosis to collect disability payments if a diagnosis was made in a later stage of the illness. The Massachusetts Congressional delegation and the state agencies concerned with these issues should try to influence the Social Security Administration to implement this change.
10. State Licensing Board examinations for medical, nursing, and allied health professionals should include questions related to the recognition and differential diagnosis of the dementias (including Alzheimer's Disease), and to the management of patients with dementia.

Legislative

1. The Federal Government should create a Medicare, Part C program which would cover specified long term care services, both institutional and non-institutional. As a first step in a strategy to implement this recommendation, the Massachusetts Congressional Delegation should be asked to introduce legislation directing the Secretary of the Department of Health and Human Services to establish a Blue Ribbon Commission charged with developing a concrete Medicare reform plan within a specified period of time.
2. Private long term care insurance should be developed as a major component of long term care financing to provide choice to those who can afford it and who may not want to rely on public programs or who may want to purchase more flexible coverage. A State Commission to study the level of need for private long term care insurance, barriers blocking the development of such insurance, and strategies to encourage the development of such insurance should be established as proposed by House Bill 93.
3. A comprehensive financing strategy should encompass changes in tax policy, including credits to families supporting a family member with Alzheimer's Disease, in order to alleviate the burden on families. Mechanisms for protecting family assets should be developed. Several current Federal bills would reform tax policy to assist families in financing care of the chronically disabled, including those suffering from Alzheimer's Disease. These could be first steps in a national tax policy to address the needs of Alzheimer's patients and their families. The bills are: S.778, S.779, H.R.467, H.R.644, and H.R.723. These bills, as well as those before the Massachusetts legislature, allow exemptions or deductions for an elderly relative, regardless of health or care needs, usually specifying that the relative must be at least 75 years old. The bills would better serve the above stated purposes if they were amended so that eligibility is based upon age or on a diagnosis of dementia of the Alzheimer's type or a related disorder.

Private Sector

1. Private employers should permit a longer period of retroactive determination of disability for Alzheimer's Disease. This would enable an individual who lost a job due to the impact of the disease prior to diagnosis to collect accumulated benefits if a diagnosis is made in a later stage of the illness.
2. Private industry, the state, health care providers, and professionals should collaborate to bring about the programmatic changes outlined in the Committee's report.
3. To insure that the recommendations of the Committee are brought to fruition, advocates must continue to actively work with the state government to achieve their goals.

POTENTIAL DEMONSTRATION PROGRAMS

- I. A demonstration adult day health program and/or adult social day care program should be established to permit families of moderately affected patients with Alzheimer's Disease to be maintained at home as long as possible. This program might include:
 - 1) programs of physical activity to help maintain the mobility of patients
 - 2) consultation from an experienced physician to provide guidance regarding the general health of the patients and the control of difficult behavior
 - 3) programs of mental stimulation to maximize the cognitive capacities of the patients
 - 4) counseling and therapeutic services for patients and their families to help them cope with the impact of Alzheimer's Disease
 - 5) the services of a trained social worker to assist families in gaining access to social services
 - 6) protected exits and outdoor exercise areas
- II. A demonstration program in a long term care facility should be established to develop state-of-the-art care for patients with Alzheimer's Disease and related disorders. This program should place an emphasis on a total care plan and innovative treatment methods, which might include:
 - 1) improved staff-to-patient ratios
 - 2) interdisciplinary diagnostic and behavioral evaluations
 - 3) careful monitoring of patients' pharmacological status
 - 4) physical security for patients while permitting maximum freedom of movement
 - 5) protected exercise areas to foster physical mobility
 - 6) provision for family member participation in the caregiving process in selected circumstances
 - 7) provision of family counseling services
 - 8) provision of short term respite care services
- III. A demonstration care-delivery and financing program should be developed to explore alternative cost-effective and care-efficient systems for caring for Alzheimer's patients. The design of this managed care demonstration program is similar to that used in HMOs and Social HMOs. This program might include:
 - 1) a financing strategy that is geographic in nature, with a fixed budget or capitated financing
 - 2) a wide variety of services so that the care that is most appropriate and least costly for patients can be provided
- IV. A demonstration program for the diagnosis and management of patients should be established. This program, operating out of a clinical center, would serve as an entry point for patients with Alzheimer's Disease and related disorders. It might include:
 - 1) a team approach to the diagnosis of Alzheimer's Disease, with individuals to provide neurological examination, psychiatric

- evaluation and psychometric testing
- 2) social service support to guide patients and families in the range of appropriate medical and community resources

V. A demonstration program for home management services should be established. This program would include specialized rehabilitative, home management and consultative services to caregivers, which might include:

- 1) availability of disciplines such as occupational, physical and speech therapy
- 2) nutrition services
- 3) adaptive equipment (e.g., handrails, lifts, transfer boards, individually designed drinking cups, etc.)

REPORT
OF THE FAMILY SUBCOMMITTEE

I. Introduction

The goal of this chapter is to illustrate the family issues associated with Alzheimer's Disease and to make recommendations based on the personal perspectives of family members. The recommendations are made in the hope of lessening the burden felt by families and decreasing the suffering of those afflicted with the disease. More specific recommendations will be made in the succeeding chapters.

To present the most comprehensive and honest description of the impact of Alzheimer's Disease on individuals and their families case examples will be used throughout the chapter. The cases are not fictional; they are based on the occurrences experienced by members of the Family Subcommittee and on testimony received from Massachusetts residents at public hearings held by the Governor's Committee on Alzheimer's Disease. Although there are commonalities in the way the disease affects each family, there are also variations in the path of the disease and its resulting impact. The more common difficulties experienced by families are shared in order to illustrate service needs and public policy issues which should be addressed.

II. Issues

Diagnostic Issues

An accurate diagnosis is key to appropriately responding and managing Alzheimer's disease and its impact on those afflicted with it. A complete medical and psychological evaluation provides important information about:

1. "the exact nature of the person's illness,
2. whether or not the condition can be reversed or treated,
3. the nature and extent of the disability,
4. the areas in which the person can still function successfully,
5. whether the person has other health problems that need treatment and that might be making problems worse,
6. the social and psychological needs and resources of the sick person and the family or caregiver, and
7. the changes you can expect in the future."¹

The period of time between the onset of the illness and the medical diagnosis is often one of depression, embarrassment and anger for the ill person, and confusion, apprehension and frustration for family members as they see the changes a loved one is going through. A daughter recalls the time of the initial stage of her father's illness:

¹Mace, Nancy L. and Rabins, Peter V., M.D., The 36-Hour Day, Baltimore, M.D.: The John Hopkins Press, 1984, p. 20.

"It was the precipice of a nightmare which was to last for years. One day he came home from work upset and discouraged - he had forgotten to shut off the crane he was operating; someone could have been hurt. Fortunately, he had remembered before any damage had been done. As he sat in the kitchen that night he expressed his concern to me. He knew that something was wrong with his brain and he said so. He retired shortly after this incident. During the following two years my father experienced more and more lapses of memory, moments of confusion and inappropriate responses to situations. The progression of the disease was slow and insidious so that at first his mistakes could be covered up. One doctor told him the confusion was caused by diabetes; another doctor said it was the shock from quitting smoking."

For one woman, the period between the onset of the illness and an accurate medical diagnosis went on for at least three years. It was a difficult time for her and her family who made every effort possible to assist her mother and adjust to her problems. The daughter shared a chronicle detailing the events which lead to her mother's diagnosis.

"Symptoms common to the disease first appeared in the Fall of 1980. At that time my mother was sixty years of age. I first became aware that her driving manner was altered. This was in contrast to her long-time conscientious driving habits. My mother continued to engage in this behavior throughout the end of 1980 into early Spring of 1981. Gradually, during this latter period, instances of increased irritability became more prevalent. The early hours of the day were peaceful. However, as noon time approached, irritable and anxious behavior became increasingly noticeable. Frequently meals were served after being only partially cooked."

"Also, at this time, my mother's consumption of beer increased. In the past she had seldom indulged in the consumption of any alcoholic beverage. An increase in memory loss and a decrease in the ability to perform simple tasks paralleled her increased interest in beer. At this time my father noticed a significant change in her personality. He initially assumed that my mother was suffering from alcoholism. We were unsure if Alzheimer's was promoting the greater consumption of beer or whether the beer was the cause of Alzheimer-like symptoms. Eventually, she could no longer remember that beer or any other beverage was something which she desired or enjoyed. This entire process was completed in the Fall of 1984."

"Throughout 1983, we were forced to severely alter her lifestyle and she became increasingly hostile. As her condition went undetected by medical personnel she passed through several phases. At first, she constantly wanted to go out. Our only alternative was to take her out in the car several times a day in order to avoid physical aggression. This type of behavior continued until the Spring of 1984. A second phase of the disease also evolved during this time. My mother began to have difficulty sleeping.

She would remain awake and mobile during the night for several continuous nights. The climax of this stage lasted approximately three weeks. On each occasion, when she would refuse to go to bed, she would not allow others to sleep either. Following this three week period her tendency to remain awake during the night became less frequent."

"It is essential to note that my mother's excessive intake of beer, her eventual desire to continually go out, etcetera, are all examples of obsessive behavior manifested by many Alzheimer's victims, each in their own fashion."

Many times this prediagnosis stage is prolonged, because the ill person refuses to be examined by a doctor or the person manages to hide his/her illness from the doctor, so as to avoid embarrassment in front of friends and families. One man took advantage of his ill wife's annual visit to her gynecologist.

"I wrote him asking that he take note of her behavior and refer her to a specialist. He ignored the request and after his report of her excellent health I had difficulty persuading her to visit another physician."

Difficulties in acquiring accurate diagnosis and even appropriate referrals for diagnostic testing are not rare. One family member recounts a full year during which her father-in-law, a high school principal, was seen by one medical doctor after another before he was accurately diagnosed.

"We look back to a time during the Summer of 1979 before he got sick, and remembered that there were some things not quite right. It was suggested to him that he have his hearing and eyesight checked. And he did, having a complete physical before the beginning of that school year. He was found to be fit."

"In January of 1980, my father-in-law, age 65, became quite ill. His first symptoms suggested to the doctors that he might have suffered from encephalitis or possibly some type of psychological problem. The illness initially manifested itself in the form of hallucinating after having run a high fever for a couple of days."

"The first doctor to see my father-in-law, other than the family physician, was a psychiatrist in the emergency room of the hospital. The severe hallucinating and anxiety was treated with the psychotropic drug, prolixin, in large doses. He responded favorably in the first couple of months to this medication, and during this period was seen on two occasions by a second doctor, the head of psychiatry at the hospital. At this time, it was determined that my father-in-law's condition was not a psychiatric disorder. He was tested and evaluated for other possibilities: thyroid malfunction, stroke, tumor, and other related neurological problems. It was after all of this that the terminology, presenile dementia, was first mentioned."

Sometimes families need advice from health care professionals on how to care for Alzheimer's patients, but doctors are often of little assistance.

"At 6:00 p.m. one day, our patient decided that it was morning. He insisted on going out with the dog that snowy evening (morning?). Nothing could convince him to stay in. Finally, I dialed the doctor's office. The doctor was out and another doctor answered. I'm sure I sounded neurotic and over-excited as I asked for advice about what to do. Should I increase medication?"

"If you can't handle him, we'll put him in a nursing home and knock him out" was the advice I received. I wasn't ready yet for that kind of advice - we were talking about my best friend, the man I loved. I knew then we were more alone than we had ever been."

In contrast to the insensitivity displayed by the medical professionals described above, some families have found physicians who have been both knowledgeable and sensitive to Alzheimer's patients and their families. Indeed, ADRDA refers families to physicians who are known to be particularly skilled in diagnosis and treatment of the disease. There are physicians who arrange family conferences, suggest family support groups, are available for telephone consultation day or night and who give families support and guidance through every stage of the patient's illness. It is hoped that a greater number of physicians will adopt this compassionate and concerned attitude.

Families often report that medications are ineffective or even exacerbate difficult behaviors. It is not uncommon for patients to be put on one medication after another. One woman's father was given so many drugs at a nursing home that he was barely conscious. "We later found out that he had also been given digitalis. My father never had any type of heart condition." Another woman, still living at home with her family, has gone through several medications.

"The most recent flare-up was followed by a change in medication. Mellaril was subsequently prescribed. However, it caused (her) to experience several seizures which resulted in a hospital stay. (She) is currently taking Haldol."

Additionally, the staff at hospitals and at long term care facilities need special training on the care of Alzheimer's patients. This is illustrated in the following example explained by the wife of a man who suffered from Alzheimer's disease.

"My husband often came into contact with lab technicians, x-ray technicians, receptionists, and nurses who had no knowledge of how Alzheimer's patients act. Example: I offered to stay near him while he was being x-rayed; the technician replied that she could handle things. In a little while, he dashed through the waiting room in his shorts and white gown, closely followed by a puzzled young woman. I caught his hand and all three of us laughingly returned to the right area." "Why didn't someone explain to me?" queried the technician."

As the disease progresses, the demands on the caregiver escalate, so that additional services are needed. A woman described the stresses of her role as a caregiver.

"As the disease advanced, my husband grew more persistent about visiting neighbors and using the bathroom at a restaurant nearby (20 times in an hour), making coffee over and over again, taking hot baths - I grew unable to keep him home and I became physically tired after the first four or five hours of the day. My daughter took him out occasionally; a neighbor gave me a few free hours a week. As nights turned into day, as my husband became obsessed with ideas and actions, I got that look that all full-time caretakers get at a certain stage. I looked haggard; I admitted that coping had become too difficult. We looked in earnest for a suitable nursing home. We tried a day care center for three days, but he just kept walking out."

If a specialized Alzheimer's day care center or adult day health program existed with special equipment and staffed with knowledgeable professionals, this man's institutionalization could have been delayed. A male companion to visit the ill man at home and take him on walks would have also helped this woman manage her husband. This woman also feels that various types of respite care could have given her enough rest to continue her caretaking responsibilities longer. Additionally, day care programs situated in nursing homes would allow patients to make gradual transitions from day care to 24-hour care. This would help to ease the emotionally difficult period of transition to institutionalization for both patients and their families.

Many families will literally work themselves physically and emotionally to exhaustion rather than place their loved one in a nursing home or institution. When one woman suggested that her depressed and exhausted mother put her father in a nursing home her mother replied, "that would be a disgrace, a dishonor, and a shame. NEVER..NEVER..NEVER... as long as I am alive." Later her mother did die of a heart attack after a particularly difficult and exhausting day of care for the father.

It is because of this stress on the family that services should be directed not just to the individual who has Alzheimer's Disease, but to all family members and others who actively provide care. Both hospitals and long term care facilities need to adapt to the special needs, concerns, and characteristics of Alzheimer's patients and their families. Many families want to be actively involved in the care of institutionalized and hospitalized patients. For example, many relatives prefer to feed patients themselves. Social workers at such institutions should recognize the needs of the family unit and communicate this to nursing and other staff.

There are many special needs that Alzheimer's patients have which can be accommodated in both community-based and institutional settings. A particularly difficult characteristic is that of wandering. One woman's father escaped from nursing homes multiple times.

that had heard of organic brain syndrome and our application was quickly processed."

The Alzheimer's Disease and Related Disorders Association (ADRDA) has come a long way in assisting families dealing with Alzheimer's Disease with information and support groups. Fewer people must now face the disease as single handedly as the women described above.

Yet, in the community families do take on the bulk of the care needed for persons with Alzheimer's Disease. However, families must depend on medical doctors, nurses, home health aides, and other health care professionals and para-professionals for information, instruction, and support. Doctors are usually the ones who initially inform families about a patient's diagnosis, prognosis, and future health care needs. Unfortunately, many doctors show little sensitivity and provide families with little useful information. One woman clearly remembers the day, in February 1978, when a neurologist informed her of her husband's illness.

"Your husband has a very rare ailment named Alzheimer's." "What does that mean?" "He has an incurable disease that slowly destroys brain cells." My questions tumbled out. "How long will he live? How do I take care of him? What will happen? Will he become violent?... on and on."

"The doctor gently raised his hand to stop my flow of words. "All we know for sure is that he will get worse." "But, but, we have no regular income - ." "Contact your social services." "When do I bring him back to you?" "There's no need to bring him back. There's absolutely no help that we can offer." "But, but," I sputtered, "somebody must have lived through life with this problem. Somebody must have made a record. You can't, you can't send us out into this strange world with no instruction. What books, pamphlets can I read? People are sent to the moon with more information than you're offering."

"The poor doctor offered to lend me this text book on Dementia by Wells. I took it and verified his diagnosis - the symptoms were familiar."

In the late Winter of 1983, another family found the doctor "rude and unsympathetic." "He offered no advice or any alternative other than nursing home care."

Often families need the assistance of visiting nurses and/or home health aides. These services are expensive and in some localities difficult to access. When families are able to access these services they are sometimes disappointed by the lack of understanding and sensitivity shown by the employees towards the patient. One woman remembers a home health aide who did little more than watch her care for her sick mother when she managed to even come at the time she was scheduled for. However, another family was able to care for their ill father at home right until his death with the assistance of a compassionate young man who lived in the home to assist with 24-hour care.

"Then, in April of 1980, my father-in-law got very sick and was hospitalized for three weeks with around the clock nurses and twice a day blood testing. His condition was wrongly diagnosed at that time as a rare, rapidly destructive brain virus. He was now being attended by a neurologist at the hospital. As my father-in-law became steadily better, it was determined that he had suffered a reaction to the medication - then prolixin."

"Late in the first year my husband initiated his father seeing the doctors in Boston after viewing a television show about Alzheimer's Disease and its treatment at a local hospital. This is when the diagnosis of Alzheimer's Disease was finally made."

Autopsies are the only way to accurately diagnose Alzheimer's Disease and related dementias. Additionally, they are used to improve our knowledge of the disease; however, they are not easy to obtain in Massachusetts as one woman reports.

"Many families in our North Shore group arranged for autopsies ahead of time and others tried to secure autopsies immediately after sudden death. Only one was successfully done. Pathologists in local hospitals would not do autopsies unless the patient died in their institution. Alzheimer's Disease patients rarely die in hospitals, usually succumbing to respiratory failure, heart problems, choking, etc."

The Continuum of Care

Persons with Alzheimer's Disease and their families have multiple health and social service needs. The need for information and support is a primary need once the diagnosis is made. One woman remembers being overcome with fear when her husband was diagnosed in New York in 1978.

"I rode home from that office in a state of horror. I glanced at my tall, slim, apparently healthy husband as he deftly handled the car. Was he really changing into someone I did not know? I forced myself, to smile at the stranger who looked just like the man I'd been married to for 34 years."

"I immediately called every agency that I thought might be able to give me advice about how to live with Alzheimer's Disease: Mental Health groups (local, state, and national levels), Help for the Handicapped, Centers for Retarded Adults, Crisis Centers, social services, and a few others. My queries were accepted kindly but only one state agency had ever heard of Alzheimer's Disease. They sent me the address of another woman who had written about the same problem."

"I searched for days in the county library for information. All I found was a one-line definition in a medical dictionary: "A hopeless brain disease."

"It was months before I realized that my husband could qualify for disability benefits. The Social Security office was one agency

"Dad was in the very bad stage of Alzheimer's Disease. Most of the time he would just mumble in Armenian and constantly hum; he was also incontinent. One time Dad ran away and walked approximately seven miles through busy intersections, along the Charles River, through Watertown Square and lots and lots of traffic until he arrived at the furniture store which he used to operate. We then transferred him to another nursing home.

He ran away again. He walked for miles beside the Charles River through two towns and squares until he came to the house that he and mother had once lived in for over forty years and raised their three children. My father walked up the front steps and rang the bell and the new owner, who was also Armenian opened the door. When he saw my father standing there he could not believe his eyes. My father bent down and picked up the mail, as he had always done for over forty years, and handed it to the man. Then my father walked past him up the stairs into the dining room and sat down at the table."

When institutional care is required, nursing homes are not the only alternative. State hospitals offer various inpatient settings. There are few specialized for geriatric patients. Still, one woman reports that Metropolitan State Hospital provided better overall care than the two nursing homes where her father was also treated.

"To my surprise and relief our experience with Metropolitan State Hospital turned out to be a positive one during most of my father's eighteen month stay there. He was taken off all medication immediately. The doctors, nurses, and attendants we met there were kind and competent. Within six weeks my father's behavior had adjusted to the point where it was thought that he could function in a nursing home. On the recommendation of the hospital social worker my father was placed in a particular nursing home. She brought him there on a Friday. We decided to give him a few days to adjust to his new surroundings. On Sunday afternoon my mother, brother, and I walked into my father's room to find him tied to a chair, naked, drugged, and in a pool of urine. I called up the social worker at Metropolitan State and told her what we had found. She said she would investigate. The next day she found my father in the same condition and returned him to Metropolitan State where he stayed until he died 18 months later. I have remained eternally grateful to the good sense, quick action, and compassion of this woman."

Financial and Legal Issues

The financial impacts of Alzheimer's Disease are catastrophic. Many persons who enter their "golden years" believing that their financial futures are well prepared are caught off guard by Alzheimer's Disease. The disease quickly consumes financial resources, leaving many families impoverished. Patients with Alzheimer's Disease are sometimes forced to retire early or are fired due to Alzheimer's disease related accidents or errors. Many must terminate their employment before their illness is recognized or diagnosed by themselves or others.

"One husband was employed as a machinist. His supervisor began to complain about his carelessness and finally discharged him because he refused to follow safety rules. The machinist became paranoid and complained loudly, calling his boss colorful names. Even though he had been an excellent worker for more than 30 years, he lost all his accumulated benefits. After several years of unemployment and the resultant unhappiness, an Alzheimer's Disease diagnosis allowed them to apply for disability benefits."

Another couple felt that at age 50 they were well prepared for their future.

"We mapped out our retirement program: several Keogh accounts, an annuity policy, the best health and accident insurance available, investments that we thought would yield both enjoyment and profit in the years ahead. As we had blocked in our schedule, the next 15 years were to be preparation years for our golden retirement."

Eight years later, the husband entered a nursing home and the wife's only steady income was \$140 per month.

It is often common for one spouse to retire early to care for an Alzheimer's patient at home. This may decrease retirement benefits. In other cases, younger persons will leave employment to care for an afflicted parent at home. One woman with a successful career in the computer industry left her job to care for her mother who had Alzheimer's Disease. This woman's mother has since died, but the family still suffers from the financial consequences of the disease. The woman's job skills have become outdated, so she and her five children must depend on welfare.

Perhaps persons who lack the guidance and assistance of family to handle their finances suffer the greatest hardship, particularly when their illness goes undiagnosed. Bills go unpaid, checks are overdrawn, and credit on charge cards is abused when Alzheimer's Disease impairs the ability to handle such affairs. What happens to these people? Who advocates for them? Maybe they account for some of the homeless of our society.

One of the greatest difficulties which families are faced with is the lack of insurance to cover the long term care. Medicare and private insurance provide coverage for diagnostic services and acute medical care. However, skilled nursing home care, custodial care, in-home services, and social services are barely covered by most insurance policies. Consumers often are unaware of the limits of their insurance policies until they are faced with catastrophic expenses. Many families are then forced to spend down their resources to become eligible for assistance from Medicaid, leaving the whole family in poverty.

Questions of how to manage finances and legal issues such as guardianship lead families to search for assistance from lawyers and legal aides. Unfortunately, many lawyers do not know of the special needs of Alzheimer's patients and their families. There is much confusion about transferring assets and allocating financial resources for Medicaid

eligibility and guardianship. For example, when Alzheimer's patients are incompetent, a court approved guardian is needed to approve medications. It is important that all families of those afflicted with Alzheimer's Disease have access to legal advice to help them plan for and manage these difficult issues.

Psychosocial Impact on the Family

Alzheimer's Disease creates changes in family roles, as well as in personality. The role of the patient, spouse, and children must constantly adjust to the roles demanded by this dementing disease. The relationship between spouses gradually changes from a loving and trusting marriage to a sort of parent-child relationship that finally culminates with one partner watching the other become unable to communicate, walk or even eat.

Often the husband must leave his employment to care for a wife afflicted with Alzheimer's Disease. He must learn a new role of homemaker and caregiver. Both partners must adjust to their new roles. Sometimes the ill wife will resent this "stranger" in her home and become abusive. Likewise, it is difficult when the man of the house suffers dementia. No longer the able breadwinner and incapable of displaying leadership, he and his partner adjust only with great difficulty. Often women must learn how to manage finances and take on other responsibilities that their husbands once handled, in addition to serving as the principal caregiver. One woman described the hardship faced by her mother and the rest of her family as they struggled to adapt to the new roles which were necessary to care for her ill father.

"My mother faced violence and the fear of personal injury from her husband of 45 years -- a man who had never been violent. She was angry and emotionally wounded by this disease, and was not under treatment; it was difficult if not impossible for her on a daily basis to believe that my father's actions were disease related. In anger, pain, frustration, and fear she fought back, sometimes threatening to leave him. Of course she did not for they had loved each other for years, but all of that was in question during the final two years of their lives together."

"My mother needed help. She turned to my two brothers and me, but in our own ways we too were suffering from the gradual loss of our father. He was disappearing before our eyes, but continued to look like himself. How could we believe the things she said, accept the anger she felt and support her when she was so critical of the man we loved so much? Yet, she was our mother and we loved her as well. Roles were reversing so rapidly that there was little time for gradual change and assimilation. Emotional dependence from two extraordinarily independent parents was not easily understood. We were individually shattered and faced with emotional conflicts previously unequalled in our lives."

In some cases, the sons and/or daughters may become the principal caregiver for their parent. Often this involves a complete role reversal in which the once dependent children take on parenting and caregiving responsibilities as they watch their parent slowly decline. It is a

painful experience which affects the individual long after the death of the patient. One woman's experience in caring for her father led to a sense of isolation which she still feels nearly a decade after his death.

Indeed, for many families the struggle with Alzheimer's Disease is a lonely experience with both physically and emotionally debilitating effects. It is a particularly difficult struggle for caregivers who live alone and have limited support from others. Many families receive little sympathy, understanding or assistance from extended family, friends and/or neighbors. One daughter clearly expresses these feelings.

"One of my deepest sources of hurt, disappointment, and anger during these years and lingering long after was the lack of support from my large extended family. No one offered to help."

The effects of the disease are often embarrassing to those afflicted and their families. It becomes difficult to manage the Alzheimer's patient in public, and socializing with friends become problematic. Old friends, so important for emotional support, tend to stop visiting and disappear as the disease progresses. The friends often feel the horror of seeing the changes in the patient, and they fear that they too could develop such a dreadful disease. This reaction of friends leaves families isolated during a time when they most need support. One woman expressed the anger which she feels long after her father's death.

"Where were the friends? Where the hell were all these people that were our friends and family. These so called 'friends,' who dined in our home for years and to whom we gave love and money and all that goes with friendship. They never called mother or came to see her. It was terrible; almost as terrible as the damn disease. There was only one; my mother's dear friend, who stood by us."

However, within the nuclear family there are often heroic efforts to care for the emotional, physical, and financial needs of the Alzheimer's patient. Families pool their financial resources, provide respite for each other, and search for health care, social services, and benefits to care for their loved ones. Support groups have played an important role in educating and providing therapeutic support to families. As they share solutions, the needs of the helper and the helped are met.

Children and other relatives of Alzheimer's patients often worry about their own genetic predisposition to Alzheimer's Disease. After witnessing the dementing effects of this disease on a loved one, they know first hand of the ravages of Alzheimer's Disease. There is some evidence family members experience an increased likelihood of developing the disease. The strain of Alzheimer's Disease striking the same family more than once is overwhelming from a psychological and financial perspective, but it is a reality some families must face.

Little is known about how individuals who do not have close family or friends cope with the disease. It can be expected that without family to provide in-home care they must need institutional care sooner. One woman visiting and caring for her husband who had Alzheimer's Disease in a nursing home worked with nursing home staff to assist another woman who

developed Alzheimer's Disease while visiting her sick mother at the nursing home. They did manage to get the ill woman to a doctor's office, but it was impossible to convince the ill woman that she was not well and in need of care. In the end, the woman was picked up by police and placed in a state mental hospital. Further study and attention to the plight of Alzheimer's patients who have no family or social support is needed.

Ethical Issues

Alzheimer's Disease raises many serious ethical issues for individuals, families, the medical profession, and our society. One of these ethical concerns faces the individual and their spouses as soon as the diagnosis is made, when they find out that they have a progressive dementia which is incurable. A wife of a patient shared her feelings.

"For 6 or 8 weeks after that diagnosis, I thought constantly about how I could manage to kill both myself and my sick husband. It seemed to be the only solution. How could I watch the husband I loved cease to be his capable, happy self, see his eyes dull, see him alienated from the world of human beings? If I could plan it right, I reasoned, he won't have to become confused and angry and fearful of everything around him and finally dissolve into a vegetable."

"Since that difficult time, at least half a dozen spouses have called me admitting that they too were entertaining the same thoughts of suicide and murder."

It is important that families receive support and counseling to help them overcome their fears and feelings of hopelessness as soon as the disease is diagnosed. The families should be informed that even though the disease is incurable, it is treatable and manageable. It is very difficult to cope with the disease, and yet family, friends, clergy, therapists and/or support groups can offer important assistance.

Caring for a person afflicted with Alzheimer's Disease is a difficult and trying responsibility. The family must make decisions for the infirm member by using their best judgment, while also trying to second guess what the infirm person would have chosen for themselves. Institutionalization, medications, and medical interventions all present complex and value laden decisions. Often there are no clear "rights" and "wrongs." At times family members must choose to protect their own welfare at the expense of the Alzheimer's patient. For example, when the strain of in-home care is too much for the caregiver or when financing care to the patient is impoverishing the spouse and/or family.

Perhaps it is in the hospital setting that families face the most fundamental and complex ethical decisions. Here families and the medical profession must work together to make life and death decisions. Often families feel they have too little control over the care of the patient. Inflexible hospital policies and/or medical personnel who lack sensitivity have sometimes superceded the wishes of family members. For example, some hospitals use D.N.R. (do not resuscitate) orders on extremely ill Alzheimer's patients as a matter of policy without consulting the families. This may destroy the last few strands of hope and sense of control that family members have.

Family members often maintain a more positive and fuller perspective of the patient than do doctors and nurses. They can still envision the patient as the total human being s/he was, instead of the demented person s/he has become. It is from this perspective that families should be allowed to participate in ethical medical decisions, such as whether the patient should be kept alive through heroic measures or be allowed to die with minimal medical intervention.

Alzheimer's patients are undervalued by our society even more than the general elderly population. Family members are often faced with rude remarks and sneers by others who don't understand or empathize with the plight of those afflicted with the illness. It is difficult to impact the values and morality of our society. However, there are steps that can be taken by the Commonwealth to improve the quality of life for patients and their families. These actions and policies should be developed in careful consideration of their ethical impact on Alzheimer's patients and their families.

III. Conclusion

Alzheimer's Disease devastates both individuals and families alike. Its impact on the individual with no family or other social supports must be even more disastrous. Families and individuals afflicted with the disease need a full range of long term care including, institutional and community-based health and social services, financial assistance, and educational services. The recommendations made by this report will certainly go a long way in advancing the quality and quantity of services for this population. However, advancements will need to be continued over time. Continued advocacy and public dialogue will be necessary to continue the progress we are making in treating the disease and its impacts.

To be a truly civilized and compassionate society we must tend to the needs of the helpless, the hopeless, the weakest, and the least vocal of our citizens. Let us resolve with the recommendations of this Committee to become a society that cares; let us meet this challenge with commitment, energy, and action. The implementation of these recommendations will assure families suffering from Alzheimer's Disease that there exists a core of support from the Commonwealth of Massachusetts.

IV. Recommendations

Diagnostic Issues

1. The Massachusetts media should be used to educate the public so the symptoms of Alzheimer's disease will be recognized early.
2. Medical professionals and para-professionals should have required training in diagnosis and treatment of Alzheimer's disease.
3. Hospitals should be encouraged not to limit the availability of autopsies only to Alzheimer's Disease patients who die in hospitals.



The Continuum of Care

1. An option for patients to wear sensitized armbands that set off alarms to prevent wandering away from the facility should be considered by long term care facilities.
2. Require on-going in-service education for nursing staff and everyone in contact with the patient (including housekeeping staff) at hospitals and nursing homes to promote sensitivity and appropriate quality care to meet the needs of Alzheimer's patients and their families.
3. Encourage nursing homes to build special units for Alzheimer's patients by offering tax breaks. Alzheimer's disease patients have special needs which are not accommodated in a traditional nursing home setting. It is also cruel to expose patients whose minds are intact to this illness.
4. Permit flexibility in physical design and construction of facilities. Bathing settings should be varied so that utilization of different bathing modes are possible on any given day depending on patients' attitude and behavior. Also, protected exercise areas, which are important for mobile patients so that residents do not become immobilized due to inactivity, should be constructed.
5. Require nursing home units to assume a total commitment to the patient and agree to continue to provide treatment even if/when the patient becomes bedridden and/or progresses to a different level of care.
6. Require implementation of the current Department of Public Health regulation that patients in long term care facilities be re-evaluated by physicians at least every six months. Families should receive prior notification of re-evaluation.
7. Permit the placement of personal items in rooms of patients (pictures and flowers, for example) to promote a "homey", loving environment for patients in hospitals and nursing homes. Patient environments should be personalized and as stable as possible.
8. Encourage development of adult day health programs and day care centers along with development of Alzheimer's units at skilled nursing facilities and intermediate care facilities in order to provide relief for family caregivers, as well as a mechanism to smooth transitions to eventual institutional placement. The population of adult day health programs and day care centers should include other types of demented patients. Facilities should have camouflaged exits and outdoor exercise areas.
9. Permit flexibility in nursing care standards to permit (and support) care of the patient by family members, caregivers, and/or friends. Occasional feeding is an activity that can be performed by caregivers.



10. Recommend that an initial joint interview take place with the facility's social worker and head nurse prior to admission of the patient to the facility and that appropriate information be shared with relevant staff.
11. Prescribe physical therapy for patients in an attempt to slow down the physically deteriorating aspects of the disease.
12. Authorize nursing staff or pharmacology consultants associated with the facility to regulate behavioral medications to prevent drug "pile-up" (due to inactivity) and/or Parkinsonian symptoms.
13. All day programs and institutional care facilities should serve Alzheimer's patients and those with related disorders with sensitivity to the special needs and characteristics of the population.
14. Visiting companion services and respite care in nursing homes should also be expanded to provide needed respite for family members.
15. Encourage the proliferation of educational and support groups for families of Alzheimer's patients.

Financial and Legal Issues

1. Lawyers and legal aides should be trained on the special needs of persons afflicted with Alzheimer's Disease and their families.
2. Literature on legal and financial issues should be made available to families of Alzheimer's patients soon after diagnosis to avoid unnecessary impoverishment of families and illegal administration of medications.
3. Allow a longer retroactive period for employment benefit applications if a worker discharged from employment as a result of early symptoms is later diagnosed as having Alzheimer's Disease.
4. The catastrophic costs of long term care should be distributed through private insurance benefits.
5. Consumers should be educated about the limits of Medicare, Medigap, and other insurance policies.

Psychosocial Issues

1. Families need to be educated about Alzheimer's Disease, both its effects on the individual and the family, as well as how to cope with the impacts of the disease.
2. The growth and development of Alzheimer's Disease support groups should be encouraged and supported.
3. The public should be educated about Alzheimer's Disease, its symptoms and impacts, as well as how to interact with individuals and their families who are suffering from the disease.

Ethical Issues

1. Acute and long term care facilities are encouraged to include family members in the care giving process in selected circumstances.
2. Counseling and therapeutic services should be developed for Alzheimer's patients and their families to help them cope with the many difficult ethical, psychological and emotional impacts of Alzheimer's Disease.

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REPORT
OF THE COMMUNITY-BASED SERVICES SUBCOMMITTEE

The person with Alzheimer's Disease usually lives in familiar surroundings until the illness becomes too taxing for caregivers and/or provider agencies. At that time, institutional care becomes the only alternative. For many people and their families, this is the painful end of community living. The experience of both subcommittee members, as well as those who testified at the hearings, attests to the fact that from the point the disease is detected, until the person either dies or enters an institution, there is a wide range of possibilities. Some services meet the needs, while other services and information are woefully inadequate.

The Community-Based Services Subcommittee looked at the available services through the eyes of a family seeking help. We considered the various stages of the disease and the wide range of needs which people with Alzheimer's Disease and their families require. Each member of the Committee was assigned an aspect of community care to examine. Meetings were used to discuss findings and cover any areas not explored during the individual's fact-finding period.

In the report that follows, recommendations by the Community-Based Services Subcommittee will be presented with a following narrative. Supporting data is also enclosed in the appendix to this report.

1. INFORMATION AND REFERRAL

There exists in the Commonwealth a complicated network of information and referral services. This system is both formal and informal. Much of the Subcommittee's time was devoted to examining this area of community-based services. Both in the material from the hearings and from the experience of Committee members, it was evident that good information and referral services were central to good care. For those persons or families who get good advice from the outset, costly and painful mistakes can be avoided.

Good primary medical care at the point of access is extremely important. Committee members were aware of physicians making essential referrals for diagnostic services, and ancillary social support services and immediately initiating aggressive and effective measures to alleviate symptoms which were amenable to treatment. Throughout the meetings, Committee members stressed the importance of well-informed medical staff. It was estimated that as many as 10 percent of the people referred to specialized Alzheimer's clinics had reversible conditions other than Alzheimer's. The possibility of misdiagnosis has great bearing on community care in that some families interviewed took no other action to seek medical assistance after a diagnosis of Alzheimer's Disease was given. Other examples of barriers to effective community-based care occurred when the diagnosis seemed to prevent aggressive medical management of other problems. Research centers have reported that the management of depression through medication can have a positive effect on patients in earlier stages. The appropriate use of good internal medicine and other disciplines such as psychiatry were also stressed. An effective information and referral system must insure access to these important services.

Committee members see the development of an effective network of information and referral as a central element in a smoothly running community care system. Some members noted variation in the quality and availability of information and referral services depending on the area. Cape Cod, with a 60+ population of over 33%, must be given special consideration.

Often people in the first stages of Alzheimer's Disease seek information in other areas. It was noted by Committee members that there is no subject index for Alzheimer's Disease in most local libraries. Several people reporting to Committee members stated that this was the first place that they sought information, and most spoke of frustration in not being able to find where to go for help.

The home care system developed and managed through the Executive Office of Elder Affairs provides state funds for twenty-seven Home Care Corporations throughout the state. Each of these must maintain information and referral services. There is variation in the way the services are provided and methods and amount of follow-up also vary within the system. Again, geography seems to contribute to the variation as it was noted that some geographic areas have access to a wider range of services.

Other primary points of access for information and referral include hotlines at hospital-based information centers, certified home health agencies, information centers at local Councils on Aging or Senior Centers, and the network of churches and temples which serve as a support or source of help to many.

In gathering information about available programs and services as though we were family members of an Alzheimer's patient, it became apparent that the system and available resources to access accurate information about this disease are often confusing and unnecessarily frustrating.

The information hotline at ADRDA (Alzheimer's Disease and Related Disorders Association) was reported to maintain the most effective information and referral capabilities, and an empathetic response was frequently reported to Committee members.

It was noted by Committee members that errors were sometimes made in the dissemination of information. These errors fell into several categories. It was strongly felt that information and referral people should have some clinical training in geriatric assessment. Examples were given where people calling for information were not encouraged to obtain a good medical assessment. Others were sent to programs not able to provide good assessment. Some families noted a lack of compassion on the part of information givers which created a negative climate of acceptance for what was often good advice. Lastly, some sources of information and referral were limited because of the limited parameters of service from the host agency. Home Care Corporations serve specific geographic areas and although information and referral is supplied to people of all ages, the services they sponsor are geared to people sixty years of age and older.

Again, we received reports of Home Care Corporations, Visiting Nurse Associations, clergy, and physicians who gave appropriate advice and were able to connect clients to services to promote effective community care. It is hoped that future efforts will be geared to the examination of models which demonstrate effective information and referral.

At the beginning of our examination of available community services, one member was assigned the task of calling facilities on a random list and asking if they had specialized services for Alzheimer's patients. Without exception, the caller was told that such specialized services existed. When questioned more specifically, most facilities failed to demonstrate any special capability to assist the Alzheimer's client. In fact, in some cases, facilities which initially stated that they had "specialized units or services" were ill-prepared to assist an Alzheimer's patient or family member.

2. RESPITE CARE

Community-based care represents a viable alternative to costly institutional care. The familiar surroundings of a patient's home often set a climate where maximum functioning can be expected. All too

often, the system breaks down and a patient has to enter an institution because the caregiver no longer has the strength and/or resources to go on. Experience of Committee members and testimony at hearings continually speaks of the exhaustion of those who work to keep loved ones in familiar community settings. The Executive Office of Elder Affairs promulgated regulations recently to make Respite Care available to Alzheimer's patients who are serviced by the Home Care network. The definition and parameters of service are described below. The Committee feels that this program is a major stride in providing respite for families.

The Executive Office of Elder Affairs is expanding the range of services available in the Home Care Program through the addition of Respite Care. The purpose of Respite Care is to prevent unnecessary institutionalization by providing temporary assistance to caregivers under stress. Respite Care is intended to benefit families by providing the care required by severely impaired elders on a daily basis. Respite services will be an important support to families of Alzheimer's Disease patients and other families who do not now receive home care services. The families of existing Home Care clients may also receive Respite Care when it is appropriate.

To encourage responsive service planning, Elder Affairs is combining a flexible service definition with an annual cap on Respite Care costs of \$1,355.00. Respite services may be authorized at the level required to meet the family's needs within the annual maximum of \$1,355.00. It is required that Home Care case managers explore and maximize all other formal and informal supports available to the family prior to authorizing Respite services.

Respite Care is the provision of one or more Respite services to temporarily relieve a severely impaired elder's family in emergencies, planned special circumstances, or from the daily stresses and demands of caring for the elder. The intent of Respite Care is to increase or maintain the capacity of an elder to remain in the community and to avoid the need for institutional care by strengthening his/her social and personal support system.

Respite Services are provided to the families of elderly individuals unable to care for themselves due to severe impairments. Respite services are provided in response to the need for relief of caregivers normally providing care to the elderly individual. Respite services may include such Home Care services as: companion, homemaker/personal care, and social day care. Respite services may also include: adult day health, skilled nursing, home health aide, and short term institutional care. Other types of service may also be provided if determined needed and appropriate for Respite Care. Appropriate Respite services are determined by the Home Care case manager based on the needs of the elder and the caregiver.

Eligible Elder is a severely or very severely functionally impaired individual, sixty years of age or older, requiring assistance for part of each day to remain safely at home.

Caregiver is an adult person related by blood or law, living in the same single or multi-unit dwelling as the eligible elder, who is the provider of daily care.

Daily Care is defined as assistance with tasks of daily living (ADLs and IADLs); supervision; social and emotional support; and, intellectual stimulation as required by the eligible elder for part of each day.

3. SPECIALIZED HOME MANAGEMENT SERVICES

Several members of the Committee called for the establishment of specialized services now available on a very limited basis. Home management services offer much to assist families providing care for patients at home.

Environmental and social adjustments can have a lasting effect on the care of patients and can be accomplished quickly and effectively through timely intervention of qualified professionals. The trained social worker can assist a family in making much-needed adjustments to meet the changing needs of the family member with Alzheimer's.

Often the environment, as well as the lack of skill in the activities of daily living, lead to severe problems in caring for the Alzheimer's patient. A registered occupational therapist can, through time-limited intervention, assist with changes and adjustments, both in the actual living space, and in the way activities are performed. The use and specialized modification of simple adaptive equipment, such as handrails or special eating utensils, can provide maximum independence for a client and can also create a safe and supportive environment for the community care of a severely impaired person. All members of the Committee felt that if services should be provided through the Home Care system, they would not only serve to assist the patients and families, but these consultative services would help strengthen the home care system by sharing knowledge and creative ideas. The possibility for consultation with specialized home management teams can do much to increase the energy and skill of family caregivers and will improve the skills of professional caregivers throughout the system. Current funding mechanisms make this family oriented home management consultation a near impossibility. Additional funds would insure this innovative and cost-effective measure.

4. EXECUTIVE OFFICE OF ELDER AFFAIRS

In its effort to identify the need for new programs to assist Alzheimer's patients, it is essential to acknowledge and support those programs which already exist to provide care.

In the past two years, the Executive Office of Elder Affairs has waged a major effort in directing the state home care system to provide more and varied services to frail elders. This policy of "targeting" services redirects resources to those who have Alzheimer's Disease and related disorders. In a recent survey by the EOEA, slightly over 2,500 individuals with a medical diagnosis of Alzheimer's Disease were being

cared for through the state home care system. This survey is an extremely conservative estimate, and it is felt that more Alzheimer's patients are being served at this time.

Several recent initiatives by EOEA enable the twenty-seven Home Care Corporations to better serve the Alzheimer's population.

Protective Services: It has been demonstrated that nearly 75% of the reported cases of elder abuse occur with people who have severe cognitive or physical impairment. When a person with Alzheimer's Disease is left in the care of a family member who lacks the instrumental skills to provide for that patient, the need for protective services is often apparent. This is not to imply that families of Alzheimer's patients are prone to abusing loved ones. The literature demonstrates that the phenomenon of multi-generational inversion can create dangerously high stress levels in families where the caregiver has long-standing patterns of dependency on the patient. The new statewide service with backing of Chapter 604 -- protective service legislation, has done much to set a climate where Alzheimer's patients and caregivers can get help when the stress becomes unbearable.

Personal Care: This service, instituted over a year ago, provides funds for personal care attendants who can give hands-on care to an Alzheimer's patient. A major benefit of this program within the Home Care network is that EOEA made funds available for three days per week of consultation by a registered nurse to each Home Care Corporation. This has recently been expanded to five days per week throughout the state. The services of professional nursing consultation geared to meet the needs of very frail elders also serves to upgrade the skills of the case managers in the Home Care Corporations who work closely with the personal care programs on an ongoing basis.

The Community Care Connection: Ten Home Care Corporations throughout the Commonwealth have been selected to participate in a project entitled, The Community Care Connection. Through a joint effort of the Department of Public Welfare and the Executive Office of Elder Affairs, Medicaid clients who would be eligible for public assistance in a level II or level III nursing facility will now be maintained in the community. Both departments will provide funds. The community coordination that has already resulted among allied agencies has strengthened networks of care.

Social Day Care: The Executive Office of Elder Affairs has encouraged the development of social day care throughout the state. The proliferation of these programs is seen as a strong measure in the development of a balanced service system of community-based care for Alzheimer's patients.

For specific definition of available services through the Home Care System, see Attachment 1 of this Subcommittee report.

5. PURCHASE OF COMMUNITY SERVICES

The complex system of purchase of services presents unfortunate barriers to the availability of community-based services to Alzheimer's patients and their families.

The State Auditor's Office, in its Blueprint for Reform has published the findings of the audits of 122 provider agencies. Twenty-three major areas of deficiency in the purchase of social and rehabilitative services have been identified. These include conflicting standards, complex regulations, non-existent statewide needs assessments, and an "unwieldy" rate setting process.

This last issue was of particular interest to certified home health agencies. Visiting Nurses Associations which testified or were interviewed by members of the Committee, expressed frustration in their conflicting desire to provide a wide range of qualified services to home-based Alzheimer's patients and the approved level of reimbursement. The Rate Setting Commission's methodology in setting historically based rates has insured that certified home health agencies care for Alzheimer's patients (with their complex and multiple needs), at a financial loss to the agency.

There must be a re-examination of the purchase of services system with special consideration for how difficulties in that system prevent the delivery of good community-based services.

RECOMMENDATIONS

Information and Referral

1. Information and referral centers for Alzheimer's Disease and related disorders should be distributed throughout the state to promote access and availability to information, as well as to capture statistical information.
2. Information and referral workers should be able to make judgements to avoid deleterious effects of inadequate and inappropriate information. They should also provide follow-up to primary caregivers to insure linkages to necessary services.
3. It is recommended that periodic assessments of services and programs for Alzheimer's patients be made and that the information gleaned from the assessment be used to develop an Alzheimer's directory which would be updated continually.

Respite Care

1. The Respite Care system initiated by the Executive Office of Elder Affairs should be expanded, and \$2,000,000 should be added annually to provide Respite Care for caregivers.

Specialized Home Management Services

1. Specialized Home Care management services geared to caregivers of Alzheimer's patients need to be made available. Social work, occupational therapy, and adaptive equipment should be available through this program.

Executive Office of Elder Affairs

1. The Executive Office of Elder Affairs is encouraged to continue its efforts to improve the home care system's capabilities to serve the most frail in the community.

Purchase of Community Services

1. The purchase of services system in the Commonwealth should be reviewed and modified to facilitate adequate professional provision of services in community settings. There must be incentives to care for indigent Alzheimer's patients who lack supportive families.

ATTACHMENTS
TO COMMUNITY-BASED SERVICES SUBCOMMITTEE REPORT

THE HOME CARE PROGRAM

The Home Care program assists frail elders to live independently in their own homes. The program offers elders, and the spouse, family, and friends who often care for them, an alternative to placement in a nursing home. Home care program funds are allocated by the Executive Office of Elder Affairs to twenty-seven Home Care Corporations, non-profit agencies who provide case management and arrange the services needed by frail elders.

A. Eligibility

Home care clients must be sixty years of age or older and meet financial criteria established by Elder Affairs. In FY '84, services were provided to a single elder if his/her income did not exceed \$8,760 and to couples whose income fell below \$11,445. The income thresholds are increased each year to keep pace with inflation. In 1985, eligibility levels will be \$9,067 and \$11,846 respectively.

In addition, Home Care Corporations conduct a needs assessment that measures an elder's functional status and his/her need for home care services. Services are authorized by case managers in the Home Care Corporations in accordance with the results of the assessment.

B. Service Package

In FY '84, the primary service package included:

Case Management	Homemaker
Information and Referral	Chore
Transportation	Home Delivered Meals
Companionship	Laundry

During the year, four new services were added: personal care as a component of homemaker services, social day care, emergency shelter, and protective services. The services are described below:

Information and Referral: Services are available to elders needing information and referral to the appropriate sources.

Case Management: Services consist of a comprehensive needs assessment, eligibility determination, and assisting the applicant to identify, accept, and secure services which may be available formally or informally in the community. Case managers are responsible for the development, implementation, and maintenance of an effective service plan for a client.

Homemaker: Services are provided to assist elders with home management and activities of daily living. These services may include shopping and errands, meal preparation, light housekeeping, and personal care.

Chore: Services assist clients in home maintenance including light and heavy house cleaning and minor home repairs.

Transportation: Services are provided to transport clients to meal facilities, medical appointments, or community facilities.

Home Delivered Meals: Services are provided to help insure well-balanced meals and proper nutrition.

Companionship: Services provide company and socialization to lonely or isolated clients.

Laundry: Service is provided to clients having no other means of having laundry done.

Social Day Care: Service is provided for meals, socialization, and recreational activity for clients needing daytime supervision.

Emergency Shelter: Service is designed to provide temporary shelter for elders without a home due to eviction, disaster, or lack of safe housing.

Protective Services: Service is provided in order to prevent, eliminate, or remedy the effects of abuse to an elder.

Information and referral services are available to elders or any person in the community, regardless of income, needing information or referral to appropriate resources within the elderly service network.

For information contact your local Home Care Corporation or the Executive Office of Elder Affairs - Elder Hotline at 1-800-882-2003.

C. New Services

The experience of the Channeling Demonstration program highlighted the importance of integrating health and social services and the need for personal care among frail clients. Personal care is a component of the homemaker/home health aide service defined by the Rate Setting Commission in its regulations governing reimbursement of services.

Personal care tasks include helping frail elders with personal hygiene (taking baths, grooming), dressing, shaving, assisting with toiletry, and helping elders transfer from a bed or chair. All Personal care tasks must be reviewed and approved by a registered nurse consultant or be recommended by a physician according to Elder Affairs' regulations.

The addition of personal care will improve the flexibility of the home care program to serve frail elders. To help train and supervise the delivery of personal care services, Home Care Corporations were allowed to hire or contract with home health agencies to provide nursing consultation.

In addition to personal care, Elder Affairs added adult social day care as a home care service.

Social day care provides an individualized program of social activity for elders who need supervision but do not need health services during the day. The supervision and activities assist elders with difficulties caring for themselves during the day. It offers a nutritious meal, snacks, and special diets if needed. Activities include recreation and social activities suited to the needs of elders which are designed to encourage physical exercise and social interaction.

Social day care, as opposed to day health care, is intended for clients who need supervision and structured activities rather than health care. Social day care is an appropriate service for many patients with Alzheimer's Disease in the early stages of the disease. It was added as a supportive service for the many families who care for frail elders. Councils on Aging and Senior Centers are expected to become major sources of adult day care services.

Two other services were implemented in FY '84, emergency shelter services and protective services. Emergency shelter services provide overnight shelter for a family or individual elder who needs shelter due to eviction, abuse, substance dependency, or other economic or unsafe housing conditions. Shelter services are limited to seven days. Protective services prevent, eliminate, or remedy the effects of abuse. Elder Affairs implemented this new service as a result of legislation establishing this program.

D. Protective Services

Implementing and developing the Elder Protective Services Program is an important new effort of the Executive Office of Elder Affairs. This program, mandated by Chapter 604 (MGL 19A s. 14-26), provides social, health, and legal services to abused and neglected elders age 60 and over. Elder abuse is defined as "an act or omission which results in serious physical or emotional injury to an elderly person."

In FY '84, the program received 1,520 reports of abuse. Case-workers assessed 1,153 reports and confirmed 945 cases of abuse. Abuse included physical battering, deprivation of necessities, and emotional harassment.

During the year, Elder Affairs established an organizational structure that included three major components:

- ° staff for program monitoring development
- ° protective service agencies
- ° an elder abuse hotline

The Protective services staff, which consists of a Program Manager, four Regional Supervisors, and a Community Representative, is responsible for program development, monitoring, and evaluation. Regional Supervisors monitor and evaluate the provision of protective services and provide training and consultation to the designated local protective services agencies.

Protective services to abused elders are provided directly by the protective services agencies. Twenty-six Home Care Corporations and one community mental health center have been designated by Elder Affairs as protective services agencies. These agencies must implement protective services in accord with Elder Affairs' regulations (651 CMR 5.00).

The critical work of protective services is carried out by protective services caseworkers. Caseworkers assess reports of abuse and provide or arrange services to abused elders. Their work, often difficult and stressful, requires an understanding of the dynamics of abuse, human needs, and available resources.

Agencies, in addition to casework, also provide homemaker, chore, transportation, nutrition, and other services to abused elders depending on their needs. Over 30% of abused clients receive such services.

Chapter 604 mandates that certain professionals - nurses, doctors, social workers, psychologists, and others - report elder abuse. To receive reports, the Elder Abuse Hotline operates 24-hours a day. The hotline receives reports both from mandated reporters and the general public. Emergency reports are referred to protective services agencies or Elder Affairs' staff on-call to provide immediate response when necessary.

While Elder Protective Services is in its early stages of development, services are available to abused elders in all cities and towns in Massachusetts. Future plans for program development include a small guardianship program, 24-hour coverage by local protective service agencies, and expansion of the number of caseworkers.

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REPORT OF THE
INSTITUTIONAL CARE SUBCOMMITTEE

Introduction

The Subcommittee on Institutional Care recognizes that, while institutionalization may not be the first choice for patients with Alzheimer's Disease, the nature of this illness is such that at some point in its course institutionalization -- short-term or long-term -- proves to be the only choice and often the best choice for patients with the disease and their families, friends, or care-takers, given the present characteristics and structure of the nation's health-care system. When that point is reached, institutionalization becomes the most appropriate way not only to ensure the safety of the patient, but to preserve the physical, mental, and economic health of both patient and family.

Yet the attempt to obtain service of high quality for the Alzheimer's patient in nursing homes or other long-term care institutions when the need arises is fraught at present with problems for the patient's family and other care-takers all along the way -- in Massachusetts and the country as a whole. They are caught in what is eloquently described as "a classic Catch-22 bind" in a recent article in the American Journal of Public Health⁴:

"...Because of the scarcity of community support services (such as respite care, day care, and in-home services), [Alzheimer's patients] get virtually no help in community living. They often cannot obtain institutional care, and in the main, will not be able to remain in hospitals beyond their need for acute care to the same extent as in the past. Their current situation is reminiscent of their no-care situation during the late 1960's and 1970's."

"It is an inescapable conclusion that nursing home care for [Alzheimer's patients] should cost more if they are to be cared for appropriately. Exactly the opposite is happening, since disincentives to the nursing home to admit such patients, combined with disincentives to acute care hospitals to permit back-up, result in reimbursement being lower for that group and the quality of care suffers. The social cost to family care givers is heavy; the economic cost of their resultant need for health care has not been calculated."

Our subcommittee therefore makes the recommendations listed below, which are based on its own deliberations combined with as much input as possible in the time available from members of the families of Alzheimer's patients and from experienced professionals. We believe that these recommendations speak on behalf of Alzheimer's patients -- a growing segment of the population who cannot speak for themselves, but whose care needs our subcommittee heard clearly and graphically described. We expect, furthermore, that the recommendations will have broad implications for

⁴Elaine Brody et al.; Volume 74, No. 12, December 1984 (p. 1383).

maximizing the quality of life of the entire long term care population of the state.

I. Recommendation No. 1: Demonstration Units

We recommend establishment of six demonstration units for care of Alzheimer's Disease patients in the Commonwealth -- in different regions of the state and within or attached to varying types of long term care facilities, predominantly multi-level nursing homes; these units should be developed as models, with appropriate regulatory and third party reimbursement exemptions built in so that there can be adequate evaluation of whether such specialized arrangements can actually improve the comprehensiveness and quality of care available for institutionalized Alzheimer's patients.

Implicit in this recommendation is the idea that the model-building effort envisaged here would include the possibility of demonstrations in types of facilities other than nursing homes, such as chronic-disease hospitals and acute-care hospitals linked to nursing and/or medical schools; the recommendation emphasizes nursing homes as the facility of choice, however, because the latter are likely to remain as the setting within which a majority of Alzheimer's patients will seek and receive institutional care. It should be noted, furthermore, that other types of appropriate models for comprehensive community care for Alzheimer's patients should desirably be developed (perhaps under the coordinating auspices of visiting nurse associations) along lines analogous to hospice care for cancer patients.

Program Guidelines for Recommended Demonstration Units

A. In-House Arrangements:

- 1) Improved staff-to-patient ratios.
- 2) Availability for all staff members of comprehensive training and psychological support related to Alzheimer's Disease issues.
- 3) Emphasis on flexibility regarding mandated "levels of care" within nursing homes, and on gearing of care plans for Alzheimer's patients to their individual functional capacities, so that such patients can more frequently "age in place" within the institution without being exposed to traumatic changes.
- 4) Completion of careful diagnostic and behavioral evaluations on an interdisciplinary basis for prospective and current residents of the institution.
- 5) Arrangements for concerned family members or friends of each patient to participate in some manner, along with the interdisciplinary team, in caring for the patient.

- 6) Assurance of good physical security for patients within the unit while permitting them to have maximum freedom of movement, including arrangements for their access to protected outdoor areas.
- 7) Emphasis on development of new patient management techniques, and on maintaining continuity in use of innovative types of therapy so that effectiveness of such therapies in patient management may be adequately evaluated.
- 8) Provision of family counseling services.
- 9) Provision of short-term respite services.
- 10) Improvement in monitoring of patients' pharmacological status, perhaps through employment of pharmacological consultants to address special problems related to patient medications.
- 11) Capacity to prepare and serve congregate meals.

B. Outreach Activities:

- 1) Development of program linkages with various community care programs, specifically those providing day care services for Alzheimer's Disease patients; and sponsorship or development, where needed, of satellite day care centers.
- 2) Provision of specialized resources (such as aides to offer short-term respite care in the home), and of training opportunities for families and community care givers (such as day care and respite care aides, medical professionals, and outreach aides), to enable these family members and care givers to increase their "coping skills" with respect to maintenance of Alzheimer's Disease patients at home.
- 3) Employment of specially trained geriatric aides to offer crisis intervention for Alzheimer's Disease cases in the community.
- 4) Arrangement of meal deliveries to the homes of selected Alzheimer's Disease patients.
- 5) Dissemination to the general public of information about Alzheimer's Disease and its impact on patients and their families.

C. Ancillary Program for Assuring Effectiveness of Model Units:

Development of congregate housing units in close proximity to the demonstration sites, in order to enable a selected number of isolated Alzheimer's Disease patients to maintain themselves outside an institution but in a protective setting that would provide them with congregate meals and a system of needed personal support services.

D. Barriers to Be Overcome in Establishing the Model Units:

- 1) Federal Regulations - Medicare and Medicaid regulatory restrictions regarding reimbursement for non-medical disability that requires community and/or institutional long term care.
- 2) State Regulations - (a) Mandated levels of care that force the State Department of Public Health to use essentially medical criteria only, for placement of patients in skilled or intermediate care settings. (b) Criteria of the Department of Public Welfare's Case Management Screening Program that emphasize medical rather than functional or behavioral categories in assessing patient status. (c) The existing penalty on provider reimbursement, levied by the State Rate Setting Commission, when nursing homes record a patient census below 98 percent of capacity -- a policy which inhibits provision of respite care in such facilities via use of empty beds.

II. Recommendation No. 2: Changes in Reimbursement Patterns

We recommend that changes in current third party reimbursement patterns for institutional care of Alzheimer's Disease patients be instituted, so as to accomplish the following three urgent objectives:

- 1) establishment of appropriate monetary incentives for institutional care providers to meet the heavy service needs of such patients on a high-quality basis;
- 2) development of a reimbursement scheme that relates specific dollar amounts to the functional needs of individuals, rather than to arbitrary "levels of care;"
- 3) prevention of the present economic disaster facing many moderate-income families in the state caring for Alzheimer's Disease patients who are virtually forced by current requirements of the third party payment system (in both its public and private forms) to impoverish themselves before financial aid becomes available to them.

A principled dialogue is needed between community and other groups acting as advocates for the Alzheimer's patient, on one hand, and all insurance organizations (including Medicare and Medicaid)⁵, on the other hand, to begin the attempt to devise a basic insurance package for assisting Alzheimer's patients and their families in paying for necessary patient care.

⁵Medicare accepts almost no responsibility currently for paying for care of the Alzheimer's patient; and Medicaid's requirement of family asset-reduction to a bare minimum before eligibility for coverage can be established is so onerous to many moderate-income families who take pride in



Moreover, all groups interested in the welfare of Alzheimer's patients and their families should work at raising the level of public consciousness regarding the current financial "disincentives" in the state's approach to long term care for such patients. These disincentives emanate, in large part, from a traditional application of the "medical model" to the care system; while medical intervention plays a significant role in the total service picture, it is usually not the key factor in the typical day-to-day management of Alzheimer's Disease patients at home and in various community settings, including nursing homes.

III. Recommendation No. 3: Creation of an Inter-Agency Coordinating Mechanism

We recommend that a policy-level inter-agency working group be appointed to develop, coordinate, and evaluate on a continuing basis the institutional care initiatives of state government with respect to Alzheimer's Disease and Alzheimer's patients.

Among the assignments to be given to such a body, the following responsibilities should be emphasized as its major initial tasks:

- 1) to oversee development and administration of the demonstration models of care called for in Recommendation No. 1; and to arrange for and monitor appropriate and effective evaluation procedures for these models;
- 2) to design and facilitate specific programmatic improvements in the state's care and support efforts on behalf of patients with Alzheimer's Disease and related disorders and their families (see Recommendation No. 4, below, for a suggested list of such changes);
- 3) to (a) arrange for circulation of the demonstration-evaluation results to concerned professional and citizen groups and the general public, and encourage participation by such groups in improving services for Alzheimer's patients; (b) seek to facilitate, on the basis of the evaluation results, needed long-range changes for the benefit of Alzheimer's Disease patients with respect to state regulatory approaches, health-insurance reimbursement structures, and systems for collection of service data; and (c) encourage other programmatic improvements in provision of institutional care to Alzheimer's patients and their families.

their tradition of "caring for their own" that they do not consider this financing mechanism (which their taxes have supported) to be of any particular help to them at present.



IV. Recommendation No. 4: Specific Programmatic Improvements

We recommend that the state, private industry, and health-care providers and professionals combine forces in a collaborative effort to bring about the significant programmatic changes on behalf of Alzheimer's patients and their families suggested below.

- 1) Implementation by the three state departments primarily concerned (Public Health, Public Welfare, and Rate Setting Commission) of program changes which would permit greater flexibility in improving staff-to-patient ratios in nursing homes, and which would allow patients to remain in the same unit within a facility even though their defined "level of care" alters.
- 2) Implementation of a requirement that the Department of Public Welfare's Case Management Screening Program place equal emphasis on both psychosocial and physical needs when performing an assessment of, and recommending an appropriate level of care for, an Alzheimer's Disease patient.
- 3) Provision by each long term care facility of: (a) adequate training, as well as administrative and psychological support, for all personnel involved in caring for Alzheimer's patients; (b) mechanisms for improved communication and mutual involvement between long term care facilities and existing community programs; and (c) opportunities for use of current community programs, where appropriate, as locales for staff training.
- 4) Provision, to the extent possible, of short-term respite care for Alzheimer's patients within long term care facilities.
- 5) Emphasis on development within each long term care facility of a total care plan -- including innovative therapies -- for each Alzheimer's Disease patient, which would also involve family members as care givers in selected circumstances.
- 6) Implementation of a requirement that appropriate in-house and attending staffs of long term care facilities be educated as to the "state of the art" regarding drug therapy and the Alzheimer's patient, with the State Department of Public Health being responsible for developing professional educational and training material along these lines.
- 7) Creation of a statewide clearing-house for employees with experience in managing and caring for Alzheimer's Disease patients within long term care institutions, so that those facilities needing staff to care for such patients can have ready access to a qualified personnel pool in a field in which it is often difficult for employers to find experienced recruits.
- 8) Implementation of the current Department of Public Health regulation that patients in long term care facilities be re-evaluated by a physician at least every six months. Patients'

families should receive prior notification of re-evaluations.

Most of the programmatic changes just suggested have both short-term and long-term aspects; although some of the suggestions could be implemented rapidly in selected institutions and situations⁶, much more time would probably be required for all of them to be carried out on a system-wide basis.

Furthermore, most of the recommended changes have far-reaching administrative implications from the standpoint of long term care institutions; they might, in fact, turn out to be rather costly for individual facilities to implement. It seems obvious to our subcommittee, therefore, that all existing third party reimbursement systems in Massachusetts -- particularly Medicaid, in the case of nursing homes -- will need to take cognizance of these possible cost increases in their payment patterns to long term care institutions. Otherwise, it is unlikely that the vast majority of such institutions in the Commonwealth will initiate an upgrading in their care programs for Alzheimer's patients along the lines recommended here.

V. Additional Areas of Concern Related to Institutional Care

Some areas of concern that members of our subcommittee considered important did not seem to be immediately amenable to solution; it was the group's feeling that no specific recommendations should be made regarding them, but that they should be noted in this report as issues requiring further study and continuing attention by both providers of care and state administrative authorities.

- A. Special Legal Services: Provisions for guardianship, conservatorship, and power-of-attorney services -- as these legal instrumentalities may apply at various stages of an Alzheimer's Disease patient's illness -- should be carefully studied by those with the necessary legal background and implemented, when appropriate for individual patients, by their care givers or other parties involved.
- B. Emergency Care and Crisis Intervention: How can such care for an Alzheimer's patient be most effectively provided? Intricate inter-relationships among families, acute-care hospitals, and long term care institutions are required if emergency care is to be rendered on a smooth and systematic basis, but the respective roles of the different care providers in the situation have not yet been clearly defined.

Who should be basically responsible for providing crisis intervention -- and how can it be routinely established as part of the needed pattern of care for Alzheimer's patients as a group?

⁶The valuable annual publication of the Women's Educational and Industrial Union (W.E.I.U.), entitled Guide to Nursing and Rest Homes in Massachusetts, might be cited in this connection as an example of a

C. Patient Survey: Discussions in our subcommittee pointed to the need for a disciplined survey of long term care institutions in the state in order to determine the actual number of Alzheimer's patients residing in them. It was suggested that the Massachusetts Department of Public Health could include, as part of its ongoing survey activities with respect to such institutions, questions that would enable it to develop such prevalence data.

D. Education Issues:

- 1) There is a need for specific efforts in medical and nursing schools to educate students about dementing illness; and even more important is the need for re-sensitizing health professionals already in the field regarding the dementias.
- 2) A regular, structured, well-coordinated statewide program of public education, covering all major aspects of the Alzheimer's Disease, would be of help in alleviating some of the problems surrounding this illness.

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service mechanism already in place that could probably be readily adapted to an effort in the desired direction: i.e., inclusion in the next edition of material on the cognitive and behavioral deficits of Alzheimer's patients and on the manner in which these are appropriately addressed in some nursing homes.

The Patient

Our subcommittee on current practice has attempted to identify who has Alzheimer's Disease in Massachusetts, where they are, who is taking care of them, and who is paying the bill. Accounting for the estimated 30 to 40 thousand patients present in Massachusetts has not proven an easy task. No single agency is counting all the groups in a consistent manner.

One reason ascertainment is difficult is the nature of the disease. Since Alzheimer's is a progressive neurological disease, there is no simple category of patient. The patients range from early cases which can be managed at home or can attend a conventional elder day care setting, to very ill terminal patients who require skilled nursing and medical care. The course of the disease is slow. Eight years is not unusual. During this decline, different levels of service are required, and the disease is not identifiable in a consistent manner at early stages.

The major categories of care are family care, a variety of home delivered services, and several kinds of institutional care. Those in institutional care are easiest to count. The Department of Public Health estimates that there are 7,500 patients in nursing homes. In addition, there may be 850 in chronic disease hospitals of the Department of Public Health, 600 in the Veterans' Administration hospitals, 250 in mental health facilities, and 125 in institutions for mentally retarded adults. This accounts for 9,325 cases and leaves somewhere around 20,000 to 30,000 cases unaccounted. These persons may be undiagnosed, alone, or in family care. They may or may not be receiving services at home.

If they are receiving home care from someone other than family or friends, they may be clients of a Home Care Corporation under the Executive Office of Elder Affairs, or private agencies, or through an informal family arrangement. We have few figures for these systems. An Elder Affairs' survey indicated that they are serving 2,300 clients with significant cognitive impairment through the Home Care Corporation. Privately arranged home care could be serving another 3,000, and the informal network could be caring for 6,000. Another 1,000 might receive help from Visiting Nurse Associations, social service agencies and Welfare. Such "guesimates" are most rough and not to be relied upon. This would leave only 17,000 to 27,000 persons with no support system other than families and friends.

The number of people with Alzheimer's Disease in the Commonwealth will continue to increase as more and more elderly reach the ages where Alzheimer's Disease is a significant risk. Between 80 and 85, 20 to 40 percent of individuals may show cognitive impairment. Their numbers, the duration of the disease, and the exceptional level of continuous monitoring required makes Alzheimer's our most expensive disease. Each new case will cost someone on the average at least \$150,000. This cost must be shared between the patient, his family, his estate and the federal, state, and local governments. How this can be done fairly and humanely is the subject of our committee's study.

The Family as Both Care Provider and as Patient

Where a patient has a family nearby, or lives with a spouse or relative, family members (most often the spouse) try to care for the patient, but the cumulative and devastating effects of the disease may turn the care giving family member into a patient as well, one who needs counselling and social support.

Alzheimer's Disease is devastating to a family. There is first and foremost the loss of the loved one, slow and relentless. The family is forced to assume a caretaker role for which it may be ill prepared. Unless there are unusual financial resources, it soon becomes clear that the family estate will be exhausted and that there may be no provision for the surviving spouse or the children. For a variety of reasons: love, dependence, feelings of responsibility about marriage or parents, cultural and family pressures, and the need to conserve resources, care at home is attempted by most families with varying degrees of success. Their intolerable situation fills families with conflicting feelings of anger and guilt, and may lead to abuse of the patient and abuse by the patient, who may become the center of a bad family situation. The quality of home care ranges from excellent to poor. Respite services become very important. When the patients enter the nursing home, as they almost inevitably must, family resources are quickly exhausted and sooner or later the imperfect Medicaid safety net comes into play.

In many ways the patient with family is fortunate. The family can see that the patient is diagnosed and provide some comfort to offset the terror of losing one's memories and identity.

The patient with no family is especially vulnerable. He or she lacks the personal and loving attention which a relative can give (when willing), as well as the advocacy protection which relatives can give. The caring relative is often the most dedicated caretaker, who finds resources, who coordinates separate services, and who keeps pressure on organized service agencies or institutions to assure that the patient's needs are not overlooked.

The single patient, lacking this back-up, may fall between the cracks of the service system, or enter the system but receive less than attentive care. Such patients are also at higher risk of entering a nursing home prematurely.

Diagnosis

Massachusetts has exceptionally good diagnostic services which offer specialist medical diagnosis, including those of a neurologist or internist. There are perhaps four units that are among the best in the nation, another six which are quite good, and foundations for another ten. A thorough medical workup may identify the patient with reversible dementia and return them to a normal life. The mobilization of supporting services may be more of a problem than providing primary diagnostic services. On the other hand, a mistaken diagnosis can cause a person to be institutionalized and placed in a position of no escape. The public and family doctors are not always aware that these diagnostic centers exist, or they may seem remote and inaccessible.

The poor, single, and medically under-served have a more difficult time. They must find their way to diagnosis without family or family doctor. They may be helped by friends, a priest, a minister or rabbi, or a social worker. With luck they may find the ambulatory care center of Boston City Hospital, a neighborhood health center, the Veterans' Administration's Diagnostic Center at Court Street in Boston, an interested Home Care Corporation or home health agency, or the Boston University Home Medical Service. On the other hand, they may be picked up by the police as a disturbed person and enter the system as a Mental Health client. They must be recognized as Alzheimer's patients among the schizophrenics, the alcoholics, and the depressed. After diagnosis, some sort of an arrangement must be made for following these cases and providing necessary support services.

Management

Good management can make things easier for everybody: the patient, the family, and the care giver. Good management is the best treatment we know. Professional home care, day care, and nursing home care can keep patients socially active and appropriately stimulated.

As the disease progresses, the patient may become more and more difficult. About the time real communication is lost, these patients may become very aggressive, angry, and active. They are difficult to care for by anybody: family, home care personnel, day care center, and nursing home. They are, consequently, exceptionally hard to place. While the decision to institutionalize may at the moment seem harsh, it may be the only solution. During this period, the cost of care in the nursing home exceeds the level of Medicaid payments. A period of apathy may follow, when active therapeutic management may easily give way to custodial care alone. It is difficult to know how much awareness the patient retains. As the illness becomes terminal, higher and higher levels of nursing and medical care are again required, exceeding the resources found in almost any private home and most nursing homes.

The Care Givers

Families, Home Care Corporations, mutual aid or support groups, home health agencies, nursing homes, and adult day care centers are among the most important care agencies. After diagnosis has been made, the number of clinically competent individuals interested in continuing care is limited. The family has often not been much help. In certain areas, such as the inner city, there may be no family doctors, their acute care role being filled by the neighborhood health center. Family doctors may not be particularly well informed or interested in Alzheimer's Disease. How to reach them with reliable information about such matters as appropriate medication deserves considerable attention. One way is through the nurses. The head nurse in a nursing home, specialized day care center, or VNA has often had extensive Alzheimer's experience. Nurses know how to talk to doctors, and good ones command their respectful attention.

Deinstitutionalization of state mental health facilities and a steady erosion of family support by private physicians contributed to the formation of Alzheimer's support groups organized by volunteers. These

groups played a major role in the organization of the Alzheimer's Disease and Related Disorders Association. Now many support groups are started by health professionals. The national, state, and local Alzheimer's organizations make extensive use of volunteers who staff the hotline telephones, write newsletters, prepare and distribute brochures, contribute to the support of research, and inform the public about the disease. Such organizations have not usually provided care. They have, in some parts of the country, organized day care and respite care.

Social agencies, particularly in the inner city, have a rich tradition of helping the disadvantaged and may be the first to spot a problem with dementia. Nutrition programs and congregate housing provide similar opportunities.

Home Care

The needs of the frail elderly have stimulated a home care and home health industry, financed by: Massachusetts appropriations to the Executive Office of Elder Affairs, by Medicaid and Medicare (limited), by Title 20 of the Social Security Act, and by the Older Americans Act. Proprietary home service agencies, mainly for homemakers and home health workers, have also proliferated, relying on a combination of private pay and public reimbursement revenue.

The Executive Office of Elder Affairs is the major provider and purchaser, through the network of Home Care Corporations established by its legislation and regulations, supported in part by its budget of approximately 100 million dollars. Many non-profit and proprietary agencies also provide their services for Alzheimer's patients under service contracts with the Home Care Corporations and the Executive Office of Elder Affairs.

There is no sharp or clear boundary which separates care at home from institutional care until the later stages of disease when institutionalization becomes unavoidable for most patients. But care at home is possible given the readiness of family members to share the care burden, family and patient financial resources, and the cooperation of home care or home health agencies, of adult day centers, and of respite services.

The comparative costs of nursing home versus care at home are controlled by the stage of severity the patient is in, and the volunteer time available from relatives or friends.

Because levels of care, and costs, shift with time, the choice between institutional or home care often requires the expert help of physicians, social workers, nurses and case managers in close association with family members. Data about costs and intensity of care is very scant regarding Alzheimer's patients. More general data about care costs in long term care conditions is available, but is not easily applied to Alzheimer's patients for reasons noted above.

The number of hours of home care which can be arranged through the Executive Office of Elder Affairs' homemakers is limited by budgetary appropriation. The programs originally created by Elder Affairs under the

Older Americans Act were for relatively healthy elders who would be able to maintain their homes with a few hours a week of homemaker services. An exemplary program was created in Massachusetts, one of the best in the country. The management of cases was not under the traditional visiting nurse or social worker, but under a new kind of case manager who has a case load at the present time of 70 cases.

Home Care Corporations, under the direction of the Executive Office of Elder Affairs, have begun to concentrate their services on the most handicapped elderly. Since they work under nearly independent boards of directors, as well as federal and state regulations, this shift is taking place at a pace more or less dependent upon the individual agency.

The need of Alzheimer's patients and their families for homemaker and personal home care services is difficult to document. A typical example of a person who needs homemaker services is an elderly man trying to care for an elderly spouse at home. The hearings emphasized the need for someone who could take care of the patient while the family had some time off. Families wanted to know very badly how they could find such persons. The hearings also raised some questions about the quality of care some patients were receiving at home from elderly and infirm spouses. There is a need, sometimes desperate, for advice of the type which can be provided by visiting nurses, case managers, a home medical service, or a family doctor. In this country and others, patients first turn to family, then to the informal network and finally to the services provided by the state or private agencies for help within their homes.

Day Care and Nursing Home Care and Hospitals

The private sector in this state has taken some Alzheimer's initiatives. The proposals by Newton-Wellesley Nursing Home and Charwell House for Alzheimer's units, and the Mayo Alzheimer's Day Care Center are commendable. They try to address the problem. The private sector should be consulted by state planning groups, but their role will be determined by the extent that Third Party Payors are willing to pay high fees for Alzheimer's patients.

Acute care hospitals can provide very good medical follow-up support for the patients of their diagnostic centers, when reimbursed, which is now customary only by private-pay patients. The University of Massachusetts, Beth Israel, McLean, and Massachusetts General are examples. In the long run, they are subject to the same financial constraints as any organization doing the same work. The traditional private academic teaching hospital in this country is under severe economic pressure. The pattern of medical care and the role of doctors in providing medical care is changing radically. Now is a good time to be looking at alternative models of long term care.

A particularly interesting component of the home health network consists of Visiting Nurse Associations. Individual associations can and have attempted initiatives with demented patients. Some of these were described at the public hearing in Holyoke.

Occasionally, proprietary homemaker and home health agencies provide in-home staff but usually for families able to pay high hourly rates.



Specialized day care centers for Alzheimer's patients are very attractive. Alzheimer's patients are an imposition on normal frail elderly who resent the distraction and staff attention they require. In the specialized day care center, the Alzheimer's patient can have friendships with the only people who know what it feels like to have Alzheimer's Disease -- other patients. In the specialized day care center, the patient is accepted for what he or she has become. There is a highly structured program of activities which is both stimulating and fun. The family can begin to let go. They can see that health professionals know what they are doing and that the patient can be happy with non-family members in a comfortable social circle. Medication can be adjusted. Thirty clients a week can be handled in a professional unit with thirteen clients present on any particular day.

There are two similar, specialized Alzheimer's day care centers in the state. These have professional staffing ratios of one to three, rather than the more conventional one to six found in most adult day care centers. The one in Medford was created by the Department of Public Health as a discretionary project. Through a waiver on Medicaid payments, there is an extra reimbursement of \$10 a day. The one in Milton was created through the initiative of a private corporation. There is another type of day care center in Cambridge with a non-professional staffing ratio of one to one. These should be studied and evaluated as models.

The nursing home industry is not seeking Alzheimer's patients, particularly of the type most families want to place. Nursing homes that accept private pay patients must maintain attractive environments. Lying awake at night listening to an Alzheimer's patient scream does not contribute to the rest of a patient with arthritis. Securing exits does not contribute to a positive environment for the other patients. Medicaid homes in which almost everyone is cognitively impaired have plenty of business. This is clearly a large market, potentially profitable, and one for which many in the industry feel a commendable responsibility. Most see a two step solution. First, is the segregation of Alzheimer's patients from the rest of the patients, to be given appropriate attention and protection. It is felt that they should have the freedom to be themselves and to do those things which Alzheimer's patient like to do. Second, the levels of reimbursement must be adequate to sustain the effort. Several determination of need requests are before the Department of Public Health to create special Alzheimer's units. These should be expedited. There is little good data about how many nursing home beds are occupied by demented patients, nor about the willingness of nursing homes to accept difficult patients at moderate rates.

The State Departments

The Executive Office of Elder Affairs has a mandate to help the elderly, and the majority of Alzheimer's patients are elderly, though not all. There are patients as young as 35, younger if one includes Down's adults. Elder Affairs has considerable financial resources and a dedicated and experienced staff. The Executive Office of Elder Affairs has had no mandate to deal with a major medical problem such as Alzheimer's in which an early and correct diagnosis can restore 15 or more percent of the dementia patients who do not have Alzheimer's to a normal life. Elder



Affairs' primary concern is with developing and delivering social support services and coordinating these with health agencies. They can and do help early patients and their families with home care, and have begun to prepare families for admitting their patient to nursing homes or monitoring a devastating illness. Case managers of Home Care Corporations will need additional training for this type of work.

Clinical competency varies among the agencies and needs to be strengthened. Cooperation between Home Care Corporations and Visiting Nurse Associations (VNAs) is desirable and developing. The case managers of the Home Care Corporations are more expert at assessing and coordinating services for clients than in diagnosing the extent of dementia. Staff reliance on the client's doctor may not be justified for all clients.

The Executive Office of Elder Affairs is to be complimented for: its initial steps in opening its Home Care Program to early Alzheimer's patients and their families, the respite program, and the system of protective services which attempts to deal with the difficult problem of elder abuse in the community. \$250,000 for respite is obviously an inadequate amount of money to spread among 27 agencies to provide respite from all possible situations. Dementia relief will be small unless additional funding is provided.

The Department of Mental Health has always had to deal with demented patients. Large numbers of Alzheimer's patients were in the former large state mental institutions. Deinstitutionalization failed to make adequate provisions for the loss of this resource, and contributed to the shortage of nursing home beds available for demented patients. It is ironic that two diseases with so much in common as schizophrenia and Alzheimer's, both biochemical diseases of the brain with obscure patterns of inheritance, should be treated so differently within the state government. In terms of number of patients, the three conditions (Alzheimer's Disease, mental retardation, and schizophrenia) are problems of approximately equal magnitude. Yet, only mental retardation has its own Assistant Commissioner.

The Department of Mental Health admits clients to its facilities based on Massachusetts General Laws, Chapter 123. Most Alzheimer's patients do not meet the requirements of this general law. Those Alzheimer's patients who are admitted to Department of Mental Health facilities are often treated in a compassionate manner.

The Department does have a mandate to care for the mental health of the citizens. Alzheimer's families need a great deal of help. Depression is rampant. Alzheimer's patients may show common psychological systems including paranoia and abusive aggression. The care giver may abuse drugs beginning with drugs prescribed for the patient. Some community mental health centers, both large and small, have done admirable work, often because of individual initiative.

Could the Department of Mental Health do more? The Department is severely over-extended as it is. There is a shortage of doctors to treat medical needs, and Alzheimer's patients create additional medical needs. The staffing ratio in its hospitals is inadequate to care for the patients, and Alzheimer's patients require a higher than average staffing ratio.

There is a demonstrated willingness to help within the Department, but to do more would require additional funding and additional committed medical staff.

The Mental Retardation Division of the Department of Mental Health has a very serious problem with its Down's adults. Many of these people will die with Alzheimer's. While they represent less than 0.25 percent of the Alzheimer's cases in the Commonwealth, their families and care givers have the same problem. They deserve a very special concern.

The Department of Public Health is involved with Alzheimer's patients in three ways, with its chronic care hospitals, with regulation, and with registration. As with the Department of Mental Health, Alzheimer's Disease is not considered a valid reason for admission to one of the Department's chronic care hospitals. Patients enter these hospitals because they have other medical problems. Many are old and demented. The Department is actively considering an Alzheimer's unit at Cushing Hospital.

The Department certifies nursing home beds for levels of care and construction. A serious problem is that dementia is not taken into account in determining levels of care, and this adversely affects payment, which reduces incentive to care for Alzheimer's patients. Too few beds may save some Medicaid dollars, but it squeezes some unfortunate families. The approval process is maddeningly slow. It is often impossible to place a loud, aggressive, medicated Alzheimer's patient without special influence.

The subcommittee was struck by the fact that no one is comprehensively counting the number of patients with Alzheimer's Disease and related disorders in the state. The Department of Public Health does keep track of a number of minor infectious diseases, but not of the disease that threatens the very existence of the health care system. Nor, is it making projections of the impact of the increasing numbers of the very old on the Alzheimer's burden.

The Executive Office of Human Services does have a small study group addressing the Alzheimer's problem.

Other Countries -- Other States

Alzheimer's Disease is of particular concern in developed societies with large and expanding populations of older people. This leaves out much of the third world which is concerned with public health, population control, and infant mortality. In most western countries, the social service system has been extended to include long term care and later a concern for Alzheimer's Disease. The United States was late in developing a social security system, and only has a rudimentary system of long term care. Much of the initiative for Alzheimer's care has come from the medical model and directly from the families of patients. Compared to a country like Denmark, America has a very heterogeneous society. There are many tensions in our health care system. The result has been much debate and initiatives surrounding particular problem diseases such as cancer, heart disease, and Alzheimer's. In some ways Alzheimer's care in the United States may be the best in the world, and in other ways is quite deficient. In other countries, entitlement for long term care is much less

likely to be means tested. The programs in the Canadian provinces and in Australia for Alzheimer's patients and their families seem particularly worthy of study. The ever increasing cost of health care and the ever increasing population of older persons is not just an American problem. Even in countries with much smaller defense budgets, some of the superior long term care programs are being severely tried politically because of costs. Better care usually costs more.

There is a difference in the cost of care and the standards of care between states in the United States, in Massachusetts and Mississippi for example. The significant differences between states are to be found less in law, than in regulations, the state budget, levels of reimbursement, and quality of service. For example, how frail are frail elderly? Is there a Home Care Corporation case manager system? Are substandard nursing homes closed down? What is the level of reimbursement for a nursing home bed? Among the states, Massachusetts has an excellent reputation. The Executive Office of Elder Affairs is highly regarded. Our nursing homes are well regulated. Our diagnostic facilities are excellent. But, it is still difficult for the Alzheimer's patient or family or care giver to find the way to help.

Funding

There are two critical points in the system. One is the degree of financial responsibility which should be assumed by the family, and the other is the level of reimbursement under Medicaid. These are the concerns of the Department of Public Welfare and the Rate Setting Commission. Fear of impoverishment leads to hoarding of resources by families when investment in day care and respite care could be very helpful. Levels of reimbursement for nursing home care and day care ultimately determine the quality of service and its availability.

There is clearly concern about how funds enter the system. Who has first access to the funding dollar, the doctor and the hospital or social service providers? These concerns must be addressed in any successful Alzheimer's care system.

Coordination

How does one design a continuum of care for the patients of Alzheimer's Disease and their care givers? How should it be financed? The committee does not have a facile solution. We are operating in a federal system which has inadequate provision for long term care. There are six departments of the Commonwealth which must be coordinated. There are major Alzheimer's industries in the private proprietary sector, homemaker agencies, nursing homes, and the drug industry. There are vocal, concerned, and politically active constituencies in suburbia, the inner city, and rural regions of the state. There must be dialogue, and it must continue after this report is submitted.

We do have some recommendations.

Recommendations

1. There should be better coordination of Alzheimer's services in the Commonwealth.
2. We recommend that when demonstration projects are set-up for the elderly by agencies such as the Administration on Aging, the Departments of Health, Public Welfare, Human Services, Mental Health, or Elder Affairs that their impact on Alzheimer's Disease patients and care givers be specifically addressed in the evaluation. Are they good models for Alzheimer's care?
3. Unless impractical, the committee recommends segregation of Alzheimer's patients in nursing homes and specialized day care centers. Proposals recommending the creation of such units should be acted upon promptly. Admission of patients with other disorders to such programs should be a matter of professional judgement by staff on the scene.
4. Reimbursement of nursing homes and day care centers should recognize the special problems presented by most demented patients at some stage in their illness. The Department of Public Health should consider a special category of level 2 care for such patients.
5. The Department of Public Health should prepare a reliable data bank on the number of Alzheimer's patients and other demented persons in the state, their family status, and their utilization of resources.
6. Area Agencies on Aging should play a major role in the dissemination of information about Alzheimer's Disease to their constituencies. Particular attention should be given to nurse practitioners and nurses who work with Alzheimer's patients, and their communication with family doctors, neighborhood health centers, and HMO physicians.
7. Spend-down provisions should be equitable, understandable, and administered in a manner which is not perceived as arbitrary. There should not be pro- and anti- Alzheimer's case managers, or the necessity for spend-down avoidance or compliance consultants. Families feel that present policy is not always fair to the care giving family.
8. If the role of the Executive Office of Elder Affairs in support of Alzheimer's patients is expanded, we urge that the professional competence of case managers to deal with demented persons and their medical problems be improved through further training, and that their case loads be reduced. We also urge that coordination between other staff and competent nurses and doctors within the Elder Affairs' system be increased.
9. It is essential that these and other issues be studied further, even after the Commission report is filed, by some arm of the Commonwealth.
10. The role of the Department of Mental Health in serving the institutional and community-based mental health needs of Alzheimer's

patients and their families should be defined by the Long Term Care Work Group. Exemplary mental health programs which serve Alzheimer's Disease patients should be evaluated and used as models for developing similar programs throughout the Commonwealth.

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REPORT OF THE EDUCATION SUBCOMMITTEE

The findings of the Subcommittee on Education are enumerated below. They are based on the investigations and experiences of the Committee members and the extrapolated testimony of the public hearings on Alzheimer's Disease. The suggestions are believed to encompass a full spectrum of the opportunities existent to educate people on all levels of involvement with this disorder.

The following recommendations are organized according to populations within Massachusetts in need of education concerning Alzheimer's Disease: 1. The General Public, 2. Paid and Volunteer Caregivers, 3. Government employees likely to come into contact with persons with Alzheimer's Disease and related disorders or their families, 4. Families and other informal caregivers, and 5. Physicians, Social Workers, and other Professionals.

1. The General Public

Tremendous strides have already been taken in improving the awareness of the general public about Alzheimer's Disease. This work must be continued and expanded so that all members of the public can:

- a. Recognize the symptoms of dementia and know how to seek diagnosis and care for family and friends should the need arise.
- b. Lend support and understanding to friends and neighbors struggling with this disorder.
- c. Understand the current limitations of Medicare and other insurance, which presently do not cover the long term care required by Alzheimer's Disease, in order that the public may make wise individual and collective decisions about the financing of such care.
- d. Consider choosing a career or volunteer opportunity in this area.

The general public should receive continued education through the efforts of non-profit organizations (ADRDA and others), the media, religious groups, school systems, and other branches of local government as well as through religious groups.

The state government should also take responsibility for the development of specialized educational materials in Spanish, Chinese, large print, and for other special populations.

Massachusetts' Board of Library Commissioners (a state organization) publishes a newsletter that is mailed to all public libraries in the state. Included in this bulletin are lists of types of books or actual titles for public education. There are also three regional divisions of the library system which circulate newsletters that suggest titles to be included in local libraries.

A letter from the Alzheimer's Education Office mailed to these four resources, briefing them of the need for inclusion of books and other materials about Alzheimer's Disease would encourage local libraries to make information available to afflicted families.

2. Paid and Volunteer Caregivers

A major effort needs to be undertaken to recruit and train additional caregivers; such as companions, personal care homemakers, respite workers, nurses aids, day care workers, etc. The development of training and certification for these positions is urgent and should be implemented by the Department of Education as well as through the regulatory processes of the state programs that utilize these workers. Additional money should be allocated in the state budget to provide for such training.

Volunteers can become an integral part of the effort to care for people with Alzheimer's Disease and related disorders. The Commonwealth can encourage such volunteerism by reaching out to religious organizations and groups such as the Massachusetts Federation of Women's Clubs, by recognizing the efforts of volunteers through giving free training, with college course credits to those taking courses in the care of the Alzheimer's patient, etc.

In particular, the Governor should meet with top religious leaders in the state in order to increase understanding of Alzheimer's Disease and to set up a system of volunteer respite workers. Religious leaders could be asked to prepare a pastoral letter to be read during a designated weekend. This letter would describe briefly the course of Alzheimer's Disease and the tremendous emotional and financial burden to the family, the need for community support, etc. The letter would end with an appeal for volunteers to provide respite care to families caring for Alzheimer's Disease victims. Training for these volunteers must then be provided.

3. Government Employees

The efforts of the various state and local government agencies now dealing with Alzheimer's Disease need to be coordinated in a number of respects, including the areas of staff and public education. Staff in these agencies, including home care case managers, social workers, police, mental health intake and assessment personnel, disability and social security staff, etc., should all receive systematic training in Alzheimer's Disease, its prognosis and appropriate management.

In addition, appropriate state departmental newsletters should carry articles on aspects of Alzheimer's Disease relevant to their personnel.

4. Families

Education for families of people with Alzheimer's Disease is vital. In addition to the general information available to the public through the media, schools, and libraries, families need specialized information and support in the following areas:

- a. referrals for both diagnosis and patient care services;
- b. description of the disease, prognosis, and "what to expect";
- c. patient management techniques;
- d. financial planning and eligibility for Medicare, Medicaid, Veterans benefits, etc.

There are three main avenues through which families may receive the needed support and education. The first is through the physicians, social workers, and professional caregivers with whom they may come in contact. Unfortunately, in the past, all too often the families knew more than the professionals, although that is now changing. The need for professional expertise in this field will be covered in the following section. Families also need legal advice about guardianship, and for the financing of care.

The second mechanism for the education of family members is through support groups. There are now sixty support groups in the Commonwealth. The Subcommittee on Families has addressed the needs of support groups in more detail. From an educational point of view, there is a need for printed material that can be distributed to group members. ADRDA of Eastern Massachusetts has developed a model kit that, when funded, can be distributed through support groups to all family caregivers. These materials should also be made available in large print and Chinese, Spanish, Portuguese, and other languages.

The third avenue for family education is through information and referral hotlines. These are potentially important sources of information for patient care professionals as well. Current programs are fragmented and uncoordinated, with each provider agency that offers a potentially useful service falling under a different government department and set of regulations with different funding sources and guidelines. Until unified, and perhaps single-entry point case management is established, families must often serve as their own case managers in this confusing "system." Therefore, up-to-date, accurate, and accessible information and referral sources are crucial.

At present this information can be obtained through the Executive Office of Elder Affairs' Hotline, the Home Care Corporations' Intake and Referral departments, Area Agency on Aging files, through Senior Centers and Councils on Aging, and Community Mental Health Centers, as well as through the United Way and ADRDA Hotlines. In addition, information and referral workers do not necessarily have training in the special needs of Alzheimer's patients. Information is not now coordinated among these sources, and as it is changing quickly as agencies modify their programs, it is not always current.

To improve this situation, it is the recommendation of the Education Subcommittee that funding be allocated to upgrade the Alzheimer's capability of existing hotlines and referral sources, to hire staff to develop and maintain accurate referral information, and to train staff and volunteers in the dissemination of this information. In addition, local information and referral facilities need training in the evaluation of local programs for usefulness to Alzheimer's families, and in teaching callers how to use referral information intelligently.

5. Physicians, Social Workers, Nurse Practitioners, Religious, and other Professionals

Most people who exhibit the early signs of Alzheimer's or a related disorder, are seen by their family doctor, or a psychiatrist, or psychologist. Education of these professionals is essential so that complaints of serious memory loss or personality change are evaluated appropriately, and referrals to specialists are made if necessary. In addition, family doctors often have responsibility for the ongoing medical management of the Alzheimer's patient, even if the diagnosis was made by specialists. Use of psychotropic medication in the management of behavioral difficulties is especially challenging and requires ongoing review of the current literature.

It is the recommendation of this Subcommittee that all physicians who treat persons in the target age group for Alzheimer's Disease be appropriately trained. Medical schools, teaching hospitals, and teaching nursing homes should include information on the causes, diagnoses, and management of dementia. Toward this end, the associate deans for curricula at the four Massachusetts medical schools should be engaged in a dialogue and urged to develop internal task forces to determine how to implement such curriculum changes both in the medical schools and, through long term care institutional rotations, in the residency programs. For physicians who were trained before current knowledge of Alzheimer's Disease was available, the Massachusetts Medical Society, specialty societies such as the Academy of Family Physicians, and medical continuing education programs should provide programs and materials to update skills in this area.

Social workers, nurses, and other health care and religious professionals who work with people who have Alzheimer's Disease and their families can be a powerful force for good. Good patient care and management and appropriate family decision-making can eliminate much of the tragedy and stress from the lives of patients and families. Once again, schools educating these professionals need to include in their curriculum materials on normal and abnormal aging and dementia, as well as internship placements in long term care facilities caring for Alzheimer's patients. And, because this is such a rapidly evolving field, continuing education is essential. Continuing education units are part of the professional recertification process for most health professionals. It is therefore necessary to develop and offer continuing education programs on Alzheimer's Disease.

It is essential that hospitals and nursing homes provide in-service training to staff and review hospital procedures in order to better care for Alzheimer's patients.

In conclusion, it is the profound hope of the Subcommittee that we have defined the areas that specifically need to be addressed in coping with this most difficult situation. We sincerely hope that the efforts of the Committee as a whole, and those of our Subcommittee, will assist in the enactment of meaningful legislation in the Commonwealth.

Recommendations

Implementation of the report could, in the view of our subcommittee, best be achieved by the establishment, within the Executive Office of Elder Affairs, of a Division of Alzheimer's Education. This division would be responsible for the implementation of the suggestions in this report with respect to dissemination of information on Alzheimer's Disease and related disorders to the general public, paid and volunteer caregivers, state and government departments and employees, and families. In implementing these recommendations, the education office would work with organizations and groups already in the field. In addition, the Alzheimer's education division would oversee the establishment of an Information and Referral Task Force.

The Information and Referral Task Force would consist of representatives of existing government and private information and referral (I & R) systems. It would be responsible for evaluating the Alzheimer's capabilities of existing I & R programs, and devise and oversee a program of upgrading in this area. In particular, the Task Force would design and implement a training program for I & R workers to enhance their ability to give useful support and information to those coping with dementing illnesses. The Task Force would also arrange for, fund or implement, a statewide Alzheimer's Resources survey for use by referring sources.

With respect to the education of physicians and other health care professionals, the Division of Alzheimer's Education should act as liaison to the Massachusetts Statewide Area Health Education Center Program (AHEC). AHEC should receive funding, through the Board of Regents and U/Mass Worcester, to implement statewide continuing education programs in Alzheimer's and to work with medical, nursing, and social work schools to encourage curriculum enhancement.

The total first year budget of the Division of Alzheimer's Education, not including the I & R project, should include two staff members and funds for workshops and educational materials. Two small, low budget workshop series already accomplished by the Executive Office of Elder Affairs have been successful in disseminating information through their own systems and to the public. These could serve as models for future work.

Our specific recommendations are as follows:

1. A Special Task Force on Information and Referral for Alzheimer's Disease and Related Disorders should be established for one year to evaluate and make recommendations for upgrading existing information and referral services. The activities of the task force should include designing a training program for I & R workers to enhance their ability to provide appropriate information and support. The task force should consist of representatives from existing information and referral systems, both governmental and private.
2. The Area Health Education Center (AHEC) program should be directed to pursue all appropriate avenues for improving professional education in regard to Alzheimer's Disease and related disorders. This should include: Developing new continuing education programs in the area of

Alzheimer's Disease and related disorders, and working with medical schools to expand the training of new physicians in the area of dementing illness.

3. An office of Alzheimer's education should be established within the Executive Office of Elder Affairs to oversee the dissemination of information to: the general public, family members, paid and volunteer caregivers, state and government employees, and health professionals. This office would oversee and implement the recommendations of the Special Task Force on Information and Referral for Alzheimer's Disease and Related Disorders. It would also work with AHEC to improve the education of health professionals. The office of Alzheimer's education should consist of at least two staff members.

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REPORT OF THE RESEARCH AND PRACTICE SUBCOMMITTEE

INTRODUCTION

Dementia is an organic disorder of the brain which is characterized by impairment of memory and other cognitive functions, resulting in the inability of affected patients to function normally and to cope with their environments. Of all the dementing illnesses, Alzheimer's Disease is by far the most common, affecting more than 50% of all demented patients. It is a relentlessly progressive condition which, starting with the subtle impairment of memory, language function and other intellectual capacities, eventually results in virtually total incapacity. As cognitive abilities decline, the affected patient becomes unable to work, take care of the household, function in a social situation, carry out activities of daily living necessary for survival in society, and eventually to manage fundamental activities such as feeding, dressing, and bladder and bowel function. Alzheimer's Disease is predominantly a disease of the elderly, although it may occur in middle-aged and even young patients. Over the age of 80, its prevalence is four hundred times as great as that under 60. In all, dementia effects some 15% of the population over the age of 65, a third of these being totally disabled at any given time. Thus, in the Commonwealth of Massachusetts it can be estimated that more than 70,000 people are affected by dementia. Of the 70,000, about 40,000 suffer from Alzheimer's Disease.

Serious attention to Alzheimer's Disease began in the United States within the last decade. With an increase in the absolute number and percentage of individuals surviving past 65, and the recognition that what had previously been called "senile dementia" and Alzheimer's Disease were identical - whether occurring before or after age 65 - medical, scientific, health care and political interest in this disorder has developed and rapidly grown. The notion that Alzheimer's Disease was a rarity, and that "senility" was inevitable have been supplanted by the understanding that this is in fact a malignant disease process, ranking as the fourth or fifth most prevalent cause of death in American society.

Alzheimer's Disease is characterized by a clinically evident decline in memory and intellect, as noted above, combined with the appearance of large numbers of "senile plaques" and "neurofibrillary tangles" seen in the affected brain at autopsy. The precise nature of these pathologic markers is unknown, although they appear to be composed of abnormal protein substances. They are easily seen and identified under the microscope in thin sections of the brain stained with special silver and other stains. The etiology, or underlying cause, of Alzheimer's Disease remains unknown, although the pace of research in this area has accelerated dramatically over the past four or five years. Although leading scientists throughout the world are considering the varied possibilities that an unusual "slow" or "latent" virus, a toxic substance, a genetic factor, a biochemical lack, an immunologic disorder, or abnormal acceleration of the aging process may underly the disease, we do not have a clear understanding of the fundamental cause of Alzheimer's Disease. Recognition of our current level

of understanding of Alzheimer's Disease is important, since it would be an error to assume that a short-range approach to the problem is adequate, and the solution is at hand. In fact, the understanding of this condition remains decades in the future; although actively pursued by increasing numbers of research teams.

The scope of the problem produced by Alzheimer's Disease has only begun to be appreciated. The reasons for this include:

- 1) Aging of the population: While in 1900 there were only three million people over the age of 65, there are now over 25 million, providing a dramatically increased population-at-risk for the development of Alzheimer's Disease. This is largely due to the success of medical and public health measures in prolonging life expectancy.
- 2) Recognition that Alzheimer's Disease and senile dementia are one disorder: This has directed attention to the massive proportions of the population affected - now clearly identified as suffering from a disease, rather than simply waiting out the end of a long and normal life.

I. Research

Ultimately, the medical, social, financial, and political issues raised by the high prevalence of Alzheimer's Disease (A.D.) must be definitively dealt with by basic biomedical research. Conquest of Alzheimer's Disease, permitting its prevention, arrest, or treatment, would alter dramatically the impact of this disorder on the elderly, their families, and the Commonwealth of Massachusetts. It appears clear that an effective means of preventing or treating the disorder is still many years away. The Research and Practice Subcommittee strongly believes that the hope of an eventual prevention or cure for this condition should not alter the necessary, immediate strategies for dealing with the management of Alzheimer's Disease.

Research is currently being conducted in the Commonwealth by a number of investigators on many issues concerning Alzheimer's Disease, including those relating to its fundamental biologic properties, diagnosis, clinical characteristics, and treatment. Some of this research is being carried out within the Massachusetts Regional Alzheimer's Disease Research Center (MRADRC) funded by the National Institute of Aging; other research is conducted by individual investigators in four medical schools and their affiliated hospitals within the state.

We do not propose that the state should engage in direct funding of biomedical research related to Alzheimer's Disease. We do believe that establishment of several regionally distributed "Alzheimer's Disease Resource Centers," exemplifying the "ideal" diagnosis and management of patients with this condition, might be of value. Such facilities should be capable of accepting patients with dementing illness at any stage of their disease, and providing and/or obtaining every aspect of medical and social care needed; they would

serve as single entry points for patients with Alzheimer's Disease and their families, and could eliminate much of the frustration now produced in the latter by efforts to discover appropriate medical and community resources without guidance.²

Research concerning the management of, and organization of facilities and funding for, patients with Alzheimer's Disease is lacking and warrants the support and attention of the Commonwealth. Studies that develop demographic projections upon which to base cost estimates under alternative models of care, such as that suggested above, would be useful to state policy makers. Investigations to assess the impact of various methods of third-party reimbursement on the quality of care of Alzheimer's patients should also be carried out.

Support of recommended resource centers and research should include grants, contracts, and waivers of eligibility, services, and financing under Medicare and Medicaid, as well as direct line-item support within relevant state-supported human services departments.

II. Practice

At present, the point of entry of any patient with Alzheimer's Disease into a comprehensive care setting is via the medical system: the patient's physician, hospital, clinic, or similar resource. Although many private and governmental facilities exist for assistance of A.D. patients and their families, access to such facilities is ordinarily through such a "medical model."

Patients with Alzheimer's Disease ordinarily pass through a series of phases:

- 1 - Diagnosis
- 2 - Treatment
- 3 - Home Care
- 4 - Institutional Care

1 - Diagnosis

It is critical that patients with dementing disorders receive an accurate diagnosis. Approximately 10 to 15 percent of dementias have been found to be treatable and must be detected before cognitive and memory changes are irreversible. Physicians diagnosing Alzheimer's Disease must be familiar with the entities involved in differential diagnosis and capable of carrying out a complete and accurate diagnosis; these entities include (among others) brain tumors, multiple infarcts, drug toxicity, depression, and hydrocephalus.

In general, expertise in neurological examination, psychiatric evaluation, and psychometric testing is necessary for accurate diagnosis; facilities must include, among other resources,

²A specific proposal for establishing such a center has been developed elsewhere, and is available for review from the chair of this subcommittee.

computerized tomographic scanning and neuroradiologic expertise. For these reasons, a "team approach" to diagnosis of Alzheimer's Disease is often useful; a number of major medical institutions have such specialized clinical teams available for this purpose, as well as for management of A.D. patients.

The Massachusetts ADRDA³ maintains a referral list of physicians and clinics especially interested and skilled in the diagnosis of dementias; it would be appropriate for the Commonwealth to develop a similar list. Resource centers, as suggested above, could also serve the function of directing patients to appropriate diagnostic facilities.

At present, insurance reimbursement for physicians' care of elderly patients with dementing illnesses has become financially unrewarding, providing a disincentive for physician interest and involvement in such cases. Review of financing mechanisms for these time-consuming "cognitive" physician services should take into account the need to place remuneration at a more appropriate level, so as to enable physicians to care for Alzheimer's patients without financial penalty.

Education of primary-care physicians in the diagnosis and management of Alzheimer's Disease remains an important goal. AHEC (Area Health Education Centers) lectures, CME (Continuing Medical Education) courses, journal publications, and information manuals and reports published by the U.S. Department of Health and Human Services attempt to maintain and improve physician competence along these lines. Our subcommittee recognizes the need for these activities and strongly supports them; but we do not believe that it would be effective for the Commonwealth to add further courses, manuals, or publications and thereby increase the redundancy of the physicians' information system. To encourage physicians, nurses, and other paramedical personnel to develop expertise in the care of patients with Alzheimer's Disease, the mechanism of including relevant questions in professional licensing examinations should be considered.

2 - Treatment

Treatment of dementias is comprised of four aspects: (a) treatment or cure of the 10 to 15 percent of treatable dementias (e.g., brain tumors); (b) treatment of contributing or exaggerating factors (e.g., Alzheimer's Disease combined with concurrent anoxia due to pulmonary disease, or A.D. exaggerated by use of sedative drugs; (c) management of troublesome behavioral aspects (e.g., sleep disorders, agitated or obstreperous behavior, incontinence); (d) therapeutic trials with experimental medications. Medical facilities undertaking care of patients with Alzheimer's Disease and other dementing illnesses should be prepared to treat in at least the first three of these modes; and research facilities will often have experimental therapeutic agents available for patients desiring such drug trials.

³Alzheimer's Disease and Related Disorders Association.

3 - Management of Patients and Families

Management of accurately diagnosed and optimally treated patients requires knowledge of and access to public and private facilities for assistance with the care of those still able to live at home yet unable to function entirely independently. Within this broad range are included patients who show only mild impairment of memory, language function, or intellect as well as those who require major degrees of assistance for survival.

Most often the social service facilities of a medical center can help in guiding patients and their families through the maze of area agencies on aging, home health aides, community health centers, health maintenance organizations, meals on wheels, visiting nurses, Alzheimer's support groups, and other available services. No one agency or facility has been identified that fully undertakes this organizational burden; the medical system provides an entry point, yet is often imperfect, especially in facilities where specialized units devoted to management of dementia do not exist.

4 - Institutional Care

Most patients with severe, progressive, dementing illnesses who survive long enough will eventually require long-term institutional care. The medical model is inadequate in this respect since acute-care hospitals are unable to manage severely demented patients requiring custodial care for protracted periods.

In the past, many state facilities aided in the custodial care of chronically demented patients; but with deinstitutionalization the availability of such beds has been markedly reduced. For example, in 1955 Massachusetts possessed 23,000 chronic institutional beds, approximately one-fourth of which were occupied by patients with late-life dementia; it now maintains only 1,900 such beds. Nursing homes fail to provide alternative facilities largely because of the high cost of these beds (\$30,000 to \$40,000 annually).

A major obstacle to sequenced, appropriately graded care of patients with dementing disorders is, therefore, the lack of low-cost or third-party-supported chronic-care facilities. It is important, however, that newly developed chronic-care facilities avoid the pitfalls of merely recreating institutions along the lines of former state hospitals.

RECOMMENDATIONS

1. Development of state-supported or defrayed-cost institutional facilities for long-term management of patients with advanced Alzheimer's Disease.
2. Development of regional multi-purpose Alzheimer's Disease Resource Centers designed for the expert guidance of patients with Alzheimer's Disease and their families throughout the course of the illness.

3. Development of day care and respite care to permit families of moderately affected A.D. patients to maintain them at home as long as possible.
4. Identification of medical facilities skilled, staffed, and equipped for diagnosis, treatment, and management of Alzheimer's patients.
5. Encouragement of health-policy research into alternative cost-effective and care-efficient models for diagnosis and management of patients with dementing illnesses.
6. Provision of appropriate financial incentives within Medicare, Medicaid, and major insurance carriers' reimbursement schedules to encourage physicians to devote additional time and attention to the problems of patients with dementing illnesses.
7. Inclusion of questions related to recognition and differential diagnosis of dementias (including Alzheimer's Disease), and to management of patients with these dementias, in State Licensing Board examinations for medical, nursing, and paramedical personnel in order to encourage expansion of professional education in this field.

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REPORT OF THE
LEGAL SERVICES SUBCOMMITTEE

Introduction

The legal issues and problems that confront the Alzheimer's Disease patient and his or her family serve only to aggravate the enormous medical and social problems that the onslaught of the disease presents. These issues arise primarily from the inadequacy of the current long term health care delivery system in the United States and the diminution of the capacity of an Alzheimer's patient over time.

Changes in the means by which the health care delivery system is financed, discussed by the Insurance and Finance Subcommittee, would help to secure access to the system while avoiding the present precondition of impoverishment for the Alzheimer's family; yet even then, many of the same medical/legal problems would remain. Similarly, while legislative and regulatory changes and increased private health insurance would help alleviate some of the legal and medical problems, we are acutely aware that that approach is long term and is undertaken in a very clouded fiscal environment. Thus, the legal issues which the Alzheimer's patient faces arise in large part from the current limitations of private and public insurance plans.

For most of those afflicted with Alzheimer's Disease, the natural course of the disease may of necessity mean such proceedings as legal conservatorship or guardianship, or require valid powers of attorney or trusts to provide for the management and preservation of the property of the Alzheimer's patient and the financial wellbeing of his family, or to help the patient qualify for Medicaid coverage. It is imperative that families seek legal advice to determine which of these proceedings are appropriate for their particular family and situation.

Some of these concepts and proceedings stem from medical necessity, others from the desire to protect and preserve whatever assets have been accumulated over a lifetime of work.

Medicaid

What Medicare and other premium-based insurance policies have been designed not to provide to the Alzheimer's patient - custodial care - Medicaid may. Medicaid, however, is not a health care insurance program. It is a welfare program funded jointly by the tax revenues raised by

federal and state governments. Upon meeting certain financial conditions, patients become eligible for basic and long term health care. Medicaid will provide hospital, long-term nursing home, and physician services; it can also provide home health care services, occupational and physical therapy, medical equipment, drugs, mental health care services, vision, and dental care.

The basic eligibility requirement for determining entitlement to Medicaid benefits is impoverishment. These medical services are often not available until the Alzheimer's family has been reduced to poverty. Although the rules for determining eligibility are detailed and complex, what the benchmark rules are designed to discern is "poverty," making one eligible to become a "ward of the state."

Without attempting to list the exceptions or to discuss here the ramifications of eligibility requirements, the general rules governing eligibility are: A person must have less than \$350 per month of income (\$442 per month for a couple) and less than \$2,000 of "countable" assets (\$3,000 for a couple). Noncountable assets include a home used as a principal place of residence, one automobile, life insurance with a face value of not more than \$1,500, and assets of up to \$500 set aside for burial expenses. If a person (or couple) has income or assets in excess of these ceilings, he will be eligible for Medicaid only to the extent that his medical expenses exceed that income or the value of those assets.

A couple's income and assets are considered together if they live together; if they live apart, their income and assets are considered separately. If one spouse is placed in a nursing home or other long term care facility, the couple is considered to live apart after one month. However, if one spouse is hospitalized, the couple is not considered to live apart until six months have elapsed. A couple's joint property is presumed to be owned one-half by each, except joint bank accounts, which are presumed to be owned entirely by the spouse applying for Medicaid.

The state can seek recovery from a decedent's estate for any Medicaid payments made after the decedent reached age 65, but only if the decedent is not survived by a spouse or dependent child.

Against this background of available health care income and government funded programs arise the legal problems confronting the Alzheimer's patient. Some arise because of the disease itself and others because of the health care system itself.

Legal Options Available for Medical and Financial Planning

Several options are available to an Alzheimer's patient who wishes to put his or her financial affairs in order and to make arrangements for his or her future care and for the continued conduct of his or her financial

* As of April, 1985.

affairs. Some of these options require that the patient be legally competent to act. Others are available once the patient becomes incompetent and may depend on what advance arrangements have been made while the patient was legally competent to act. The options, both for the patient and for his family, include durable powers of attorney, trusts, conservatorships, and guardianships. However, it is equally important to avoid converting a supportive family relationship into a divisive one. The appointment of a guardian and/or a guardian ad litem may become necessary or desirable although such a step is expensive and can limit flexibility.

Preliminarily, it is important to be aware of several general considerations which may influence choices among the available options and which affect all aspects of medical estate planning for a person with diminishing faculties.

Foremost, it is vitally important that the Alzheimer's patient and his family get competent legal advice as early as possible. Patients and their families must be educated as to the need to seek legal help without delay. It must be recognized that the average general practice attorney may not be sufficiently knowledgeable about sophisticated planning devices and, therefore, may present the client with a more limited range of options. Legal education for lawyers as well as the use of new or existing referral services, may be helpful in order to provide Alzheimer's patients with the degree of sophistication appropriate for their circumstances and resources.

Planning Options Available to the Patient Before Incapacity

Two important tools are available to an Alzheimer's patient to provide for continuity in the management of his financial affairs. Vehicles are also available in an effort to preserve some assets for his family by qualifying for Medicaid.

A. Durable Power of Attorney

A durable power of attorney is a power of attorney which remains effective upon the disability or incapacity of the principal. Acts done by the attorney-in-fact pursuant to the power have the same effect as would acts done pursuant to an ordinary power of attorney if the principal were not incompetent or incapacitated. The attorney-in-fact can be given broad authority to manage the principal's affairs, but, under the common law of agency, the attorney-in-fact cannot make a will or create a trust on behalf of the principal (although he can fund an existing trust), nor can he make gifts except as specifically authorized in the power. The person appointed attorney-in-fact need not be an attorney at law; a family member or friend may be appointed.

The need for a durable power of attorney must be anticipated; the power must be executed while the Alzheimer's patient is still competent. Pursuant to a durable power of attorney, the attorney-in-fact can be given powers similar to those of a conservator although not as extensive as those of a guardian. The execution of a durable power of attorney requires

some advance planning, but it allows a smooth transition when incompetency ensues, without the expense and delay of a conservatorship or guardianship proceeding. There are no expressed durational limitations on durable powers of attorney, but there is some support for the view that the power is, by its nature, temporary, and that a conservator or guardian must be appointed in the event of a long term disability.

A durable power of attorney can nominate a conservator or guardian, and such a nomination is entitled to great deference by the court. Once appointed, a guardian or conservator, whether or not nominated in the power, may revoke the durable power of attorney.

One drawback to the use of a durable power of attorney is that the competence of the principal at the time of execution will always be open to question by persons with whom the attorney-in-fact wishes to deal. While resort to the courts may ultimately be necessary, such a power of attorney can be of great importance to the family of the Alzheimer's patient.

Trusts

Trusts can be used to ensure continuity in the management and control of the patient's property, to provide for gifts and other dispositions of property after the patient becomes incompetent, and perhaps to qualify the patient for Medicaid without completely divesting him of his assets. As noted earlier, eligibility for Medicaid is dependent upon a finding of poverty. Therefore, transfers in contemplation of eligibility - whether to an individual or a trust - are of great concern to the Alzheimer's patient and family.

If a person transfers assets for the purpose of qualifying for Medicaid, he may be disqualified for a period of two years (except insofar as his medical expenses exceed the value of the property transferred). However, if institutionalization or other expensive medical care can be anticipated by two years, steps can be taken to ensure that a person can qualify for Medicaid without first having expended all of his own assets for medical care. Gifts can be made and trust established. Non-exempt joint property and bank accounts can be transferred to the healthy spouse. Even exempt joint property (such as a house) can be transferred to the healthy spouse so that, in the event the healthy spouse predeceases, the property will not be subject to a claim for Medicaid reimbursement.

Finally, if institutionalization can be foreseen, a person can attempt to preserve his assets by placing them in an irrevocable trust over which he retains neither interest nor control. This is not a vehicle recommended or endorsed by the committee, but one which is currently in use. It remains to be seen if this device will effectively qualify persons for Medicaid benefits.

Options Available to the Family Once the Victim Becomes Incapacitated

If adequate arrangements have not been made before an Alzheimer's patient becomes unable to manage his or her own affairs, the family may need to resort to the Probate and Family Court in order to have someone

duly authorized to manage the patient's affairs, care for his property, and to a limited extent, arrange for the disposition of the patient's estate during his life or at his death. In this situation, the only option may be the appointment of a guardian or conservator. The desirability of seeking such an appointment depends on factors such as the extent and size of the estate, and the course of care contemplated for the patient, including the role of family members.

Conservatorship

A conservator may be appointed by the probate court for a person who, by reason of advanced age, mental weakness, or physical incapacity, is unable to care for his property. This procedure is instituted by a petition brought by the person or "one or more of his friends." Unless the person for whom the conservator is to be appointed is himself the petitioner, or assents to the petition, seven day's notice must be given to his heirs apparent and his spouse. (In any case in which the person is entitled to veteran's benefits, notice must be given to the Veterans Administration.) If, after hearing, the probate court finds that the person is incapable of properly caring for his property, a conservator is appointed to take charge and manage all of the property of the person under conservatorship. All of his actions are "subject to the direction of the court." A person may nominate his conservator if he is competent at the time of the proceeding or pursuant to a durable power of attorney previously executed while competent. The court will give great deference to the wishes of the person for whom a conservator is to be appointed.

Guardianship

A guardian may be appointed by the Probate and Family Court for a person who is mentally incompetent. The procedure may be instituted by a parent or two or more relatives or friends. The court may require an examination of the person. If the court finds that the person is "incapable of taking care of himself by reason of mental illness" it will appoint a guardian. A person may, while competent, nominate his guardian pursuant to a durable power of attorney.

A guardian has all of the powers and duties of a conservator but, in addition, he has the care and custody of the person as his ward. Thus the guardian has the authority to make routine decisions regarding the living arrangements and medical treatment of his ward. However, a decision to give or withhold extraordinary medical treatment must be made by a judge on the basis of the "substituted judgment" test.

Treatment With Anti-Psychotic Medication

While a guardian may admit his or her incompetent ward to a hospital or nursing home facility, he or she cannot, without prior court approval, make decisions regarding the use of antipsychotic drugs in a nonemergency situation. In that case, the Court must make the decision on the basis of "substituted judgment" after a court appointed guardian ad litem has made

an independent investigation, gathered the opinion of experts, family and presented his findings to the Court. If, after hearing, the Court approves the request for use of antipsychotic drugs, the Court may then delegate to an independent person, the power to assent to the administering of the medications and to monitor the treatment process to ensure that the proposed treatment plan is followed. As Alzheimer's Disease progresses, antipsychotic medications may be recommended by physicians to alleviate behavioral symptoms such as severe agitation and wandering. Current law and court practice provides safeguards to make sure that such extraordinary treatment programs are not abused.

On the other hand, heavy tranquilizers that are often used to treat Alzheimer's patients are not classified as antipsychotic drugs. Therefore, guardians or family members may make decisions regarding the use of this type of medication after direct consultation with nursing home and medical personnel.

A similar procedure is followed where the judicial decision must be obtained to give or withhold extraordinary medical treatment.

Gift-Giving and Estate Planning by Guardians and Conservators On Behalf of Their Wards

In addition to their other routine powers, a conservator or guardian may be authorized by the Probate and Family Court to dispose of the ward's property in a manner consistent with the ward's ascertainable wishes. It is presumed that the ward would wish to minimize income, estate, and inheritance taxes. Disposition of the ward's property may include the making of gifts, the exercise of powers of appointment, the creation of revocable or irrevocable trusts, and the disclaimer or release of various rights of the ward. The guardian or conservator may not, however, make a will on behalf of this ward. Gifts may be made for the benefit of prospective legatees, devisees, or heirs apparent of the ward, or to individuals or charities in which the ward is believed to have an interest.

This procedure is instituted by a petition brought by the guardian or conservator. Notice to interested persons and a hearing may be required. Thus the procedure can be cumbersome and expensive. The Probate and Family Court has the discretion to allow or deny the petition. The statute does not specifically authorize the guardian or conservator to make transfers in order to qualify the ward for Medicaid, nor does it specifically disallow it.

Legal Resources

As has been discussed previously, the legal issues facing Alzheimer's patients and families break down into two main categories: management of the patient's financial and legal affairs and management of the patient's medical care. The financial/legal issues, especially, should be handled as early as possible after the onset of the illness.

The legal services available to deal with these issues are for the most part limited to the private bar, and in most cases, the patient or his family must finance this legal assistance themselves. There is no legal service group that provides legal services for these kinds of issues specifically, although the Elder Law Projects deal with some related issues.

In the case of the Elder Law Projects, the person seeking legal assistance must be sixty years or older with sociological and economic need. These Elder Law Projects are funded by the federal government under Title III. They are usually administered in conjunction with local Legal Services programs. The stated mandate of these projects is to provide legal assistance for qualified elders in the areas of Medicaid, Medicare, Housing, Veterans' Benefits and Utility shut-offs. Issues of estate and financial planning are not specifically included, although some programs do provide limited services in establishing conservatorships and guardianships in emergency situations.

For low-income patients, another source of assistance is the various pro bono referral panels such as the Boston Bar Association Volunteer Lawyers Project and the Massachusetts Bar Association Referral Service. (The latter does not provide free services, but refers persons to lawyers, who according to the Referral Program, charge ten dollars for the initial interview.)

Other legal organizations, established to deal with similar issues, such as the Mental Health Legal Advisors Committee and the Developmental Disabilities Law Center, do not provide legal assistance to Alzheimer's patients and their families.

The Executive Office of Elder Affairs has on staff an attorney who coordinates and develops legal services for the elderly. Through efforts of this office and in conjunction with the Massachusetts Continuing Legal Education New England Law Institute (MCLE-NELI), training programs for lawyers in these areas are offered on an annual basis. As an offshoot of this program, a list of attorneys familiar with the issues of financial planning and various eligibility requirements for Medicaid and other state and Federal assistance has been developed. This referral list is available from the Alzheimer's Disease and Related Disorders Association (ADRDA).

Nursing Home Admissions

For the middle-income patient and family with some accumulated assets, trying to arrange for the present and future care of the patient and at the same time legitimately preserve some of those assets for family members who have contributed both to the accumulation of those assets and the care of the patient, the dilemma becomes further complicated by the present nursing home situation.

Because of the explosion in the need for such care, nursing home beds in general are at a premium and beds in "good" nursing homes are eagerly

sought. Many families find themselves in negotiations with nursing home administrators who require proof of ability to pay privately for several years of care. If the patient still has financial resources at the time nursing home admission is sought, the nursing home has every right to pursue private payment; even if transfers to family members have already been made, the nursing home will inquire into these transactions. Although the family is not legally required to provide this information, these factors will enter into the negotiations between the nursing home and the family. In these negotiations, the family must balance conflicting realities in trying to reach a satisfactory agreement with a particular nursing home.

For the patient who is already on Medicaid at the time nursing home care is sought, the patient may encounter further problems in gaining admission. Massachusetts nursing homes that have Medicaid contracts with the state are required to accept patients on a first come, first serve basis so long as their care is appropriate for that particular patient. Despite this and other state and federal prohibitions against limiting admissions to private pay patients, "discrimination" against Medicaid patients is in fact a problem.

Given the heavy demand for nursing home beds, it is even more difficult to prove the true basis for a denial. It is not always easy to determine if a response from a nursing home that there are "no beds available" is based in fact, or based on a desire to limit admissions to private-pay patients.

In the event that a family feels that it is being discriminated against in nursing home admissions, it should seek assistance, either from a private attorney or from an agency, such as the Attorney General's Consumer Division or the Executive Office of Elder Affairs Long Term Care Ombudsman.

Employee Benefits

For some persons who are diagnosed as having Alzheimer's Disease, the course of the illness may begin while the person is still employed. Various employment-related legal issues can arise such as a dismissal because of "incompetence," which, in turn, can cause a person to lose out on various employee benefits such as a pension or retirement privilege. A patient who encounters this situation should seek legal assistance to determine if anything can be done to recover these benefits.

Recommendations

The legal tools, devices and strategies discussed in this report are merely responsive. They only provide a means by which the informed Alzheimer's patient and family can attempt to combat the present inevitability of medical and financial devastation. At best our discussion reviews responses to a progression of medical and financial debilitation which results, both because of the nature of the disease and because of the present inadequate financial structure of long term care, for Alzheimer's patients.

While the nature of the disease for the foreseeable future must be accepted as a given, the method of financing long term health care is not quite so immutable. An attempt to change the system must be made. With that in mind, we endorse the following recommendations made by the Subcommittee on Insurance and Finance and suggest others of our own:

1. The federal government should create a Medicare Part C program which would cover long term care services, both institutional and home health care.
2. Private long term care insurance should be developed.
3. Changes in tax policy, exemptions, and credits should be explored.
4. The state should consider the creation of a legislative planning and strategy committee to work toward developing a national strategy to enact new federal legislation.
5. The states' Single State Agencies should consider monetizing the value of a spouse's homemaker services in determining the spouses' share of joint assets, and other equitable criteria.
6. Seminars and educational materials on the medical and financial needs of individuals with long term chronic disabilities should be made available to practicing attorneys. State and local bar associations should be invited to coordinate these efforts, and further develop informed legal services to handle the special needs of Alzheimer's patients and families.

In addition, there are two issues which the legal subcommittee is not currently in a position to endorse as recommendations, but which it believes worthy of consideration by the legislature and the legal community. They are:

1. To give the Probate Court specific authority to determine title to marital assets in actions other than divorce or separate support after consideration of the parties' various economic and noneconomic contributions to the marriage in general, and to the acquisition of the assets in particular. It has been suggested that a standard similar to that set forth in G.L. c.208, §34 may be appropriate for this purpose.
2. To allow a person to nominate, in a duly executed durable power of attorney (G.L. c.201B), a person who may make "substituted judgments" for him when called for under the law, including, without limitation, the authority to make a decision such as whether to accept antipsychotic medications. It has been suggested that such a nomination not be binding upon the Court, but be subject to the same type of appointment procedures that currently exist for conservators, guardians and executors

Justice Mary Muse -- Convener

Senator Jack Backman
Stefanie Cantor, Esquire
J. Elizabeth Cremens, Esquire
Julie Gregory, Esquire
Marcia Mobilia, Esquire
Anthony Sandor, Esquire
Anthony Senecal, Esquire
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REPORT OF THE INSURANCE AND FINANCE SUBCOMMITTEE

Introduction

A number of scientific advances, as well as emerging public awareness about Alzheimer's Disease and related disorders, have brought the plight of cognitively impaired elders into sharp focus. Alzheimer's patients and their families face financing problems that are not addressed by the currently fragmented health care system. In order to meet these financing problems, a comprehensive and coordinated approach will be required in the future. In an attempt to frame the parameters of such a coordinated and comprehensive system, the Insurance and Finance Subcommittee formulated a set of principles which identify key issues for consideration and aid in the preparation of short and long term recommendations for each financing problem. These principles are listed below.

Principles for Consideration of Insurance and Financing Issues

- 1) The relationships between the public (federal and state government) and the private sector's (individuals, families, and private insurers) responsibility for the care of the Alzheimer's patient should be addressed.
- 2) A broad rather than a narrow or categorical approach should be taken in addressing financing issues. Although individuals suffering from Alzheimer's Disease and related disorders are the primary focus in this analysis, some examination of care for other types of chronic patients is important in developing a rational system.
- 3) Benefits to be covered must be defined at three levels: given the trajectory of services needed, 1) what services are covered and available must be identified and what unmet needs remain must be delineated; 2) how to finance unmet needs must be examined; and 3) the feasibility of various financing options is important in developing specific recommendations for financing changes.
- 4) Consideration should be given to the total amount of dollars going into long term care and examination made of whether transfers and reallocation of resources within the current system will meet existing needs. Examination of relative equities of different sources of payment is also an important issue for consideration.
- 5) Where current funds are not sufficient for benefit coverage, the Committee will look at specific financing options for generating additional dollars.
- 6) Private, voluntary long term care insurance is likely to be a partial solution to the problem.

- 7) Changes in tax policy, including credits to families supporting a family member with Alzheimer's Disease should be explored and specific recommendations developed. Other mechanisms for protecting a family's assets should also be explored.
- 8) The relationship between Medicare and Medicaid coverage of chronic conditions is a financing issue requiring attention. The need for flexibility in Medicare to prevent spend down to Medicaid will be examined.
- 9) The issue of entitlement versus means-tested public programs for chronic care will require consideration.
- 10) The feasibility of financing strategies that are geographic in nature should be explored. Specifically, consideration should be given to a fixed budget approach which combines the organization and delivery of care with financing. Models can be found in HMOs, S/HMOs, and programs in several European countries.
- 11) There is a need to educate the population on the scope and limits of existing insurance coverage.
- 12) In addition to financing options for services or financial relief for families, funding should be supported for research or early detection and treatment.

Policy Considerations

A threshold issue critical to financing is whether broad versus categorical approaches should be taken to financing and delivery of long term care services to the elderly. In considering the problems of Alzheimer's patients and their families, there is a temptation to develop programmatic responses which are specific to the Alzheimer's patient and which limit eligibility to only those persons suffering from this type of disorder. It is our premise that such a narrow, categorical approach in many instances performs a disservice, not only to other elders in need of long term services, but to the Alzheimer's patient as well.

A crisis situation exists for elders who require long term services because of chronic disorders. To address only one such condition will further fragment the system and exacerbate the current level of competition among providers of service. A coordinated approach which considers functional capacity and need for service regardless of specific diagnosis is more likely to improve the quality of life for more people while avoiding many of the negative consequences of disease specific categorical programs. This broad approach does not, however, preclude development of some Alzheimer's specific programs within a long term care system.

Policy makers have just begun to address the difficult resource allocation decisions in the health care system related to care of elders. These difficult policy questions will escalate with growing rates of service utilization and need for chronic care associated with an aging population and therefore increased prevalence of disorders such as Alzheimer's disease and other chronic impairments. There is a further, as yet unanswered, societal question regarding the appropriate balance between public support for such programs versus the individual responsibility of elders and their families. Under current arrangements, public policy regarding this important issue is unclear. On the one hand, Medicare coverage for acute care is, for the most part, available to elders regardless of income. Medicaid coverage for long term care, however, is more limited, aimed toward those who meet certain income and asset tests. Inequities arise from legal interpretation of regulations which require some families to become impoverished through "spend down" before becoming eligible for services; whereas other families are able to "protect" family resources by transferring assets and therefore giving the appearance of impoverishment. A careful review of system-wide eligibility rules as well as consideration of means-tested sliding fee scales is recommended.

In the current political climate, it is unlikely that any one payor will be willing to accept full responsibility for financing long term care. Responsibility for care must be shared by the public (federal and state governments) and private sectors (private insurers, individuals and families). A coordinated all-payor effort between Medicare, Medicaid and private insurance would allow for the spreading of the costs over each of the payors, and thereby reduce the burden on any one.

A comprehensive and coordinated approach to financing will provide viable options and encourage choice for victims who wish to avoid "spending down" personal resources to qualify for Medicaid assistance or transferring accumulated assets to family members to qualify for means-tested public programs. Availability of private long term care insurance would provide an additional financing element for the middle class who are able to afford private insurance premiums. Expanded Medicare coverage for long term care services could provide protection for Medicare beneficiaries. Medicaid, either through long term care services currently provided for low income individuals, or through a buy-in to new Medicare coverage, could continue to provide a safety net for the low income person with Alzheimer's Disease or other elders in need of long term care. Elders and family members who have the means and chose to take financial responsibility would continue to have the freedom of choice to pay privately for needed services.

Given the above considerations, we recommend a comprehensive rather than a piecemeal financing strategy that:

- 1) combines a number of financing components requiring coordination (Medicare, Medicaid, private insurance, HMOs, self-pay);
- 2) includes federal and state tax policy which protects family assets, and provides tax support for private purchase of services as well as incentives for the purchase of private insurance;

- 3) coordinates responsibility between the public sector, private sector, families and individuals in a way that each component supports the other;
- 4) encourages better coordination between all State agencies currently responsible for policy development and/or provision of services to individuals with Alzheimer's and their families, including the Governor's Office of Human Resources, the Executive Offices of Human Services and Elder Affairs, and the Departments of Public Welfare, Mental Health, Social Services, and Public Health;
- 5) develops standards of care which incorporate managed care concepts;
- 6) maximizes choice for Alzheimer's patients, their families and other elders in need of long term care.

The Subcommittee recognizes that the development of such an ideal system is not possible in the immediate future, and that key elements such as Medicare reform may require a major political strategy. However, we believe this is the appropriate and necessary long range direction for overcoming the fragmentation of the current system and achieving a system of coordinated care for elders with Alzheimer's Disease, related disorders, or other serious chronic impairments.

Recommendations

In order to overcome the fragmentation of the current system and achieve a system of coordinated care for elders with Alzheimer's Disease, related disorders and other serious chronic impairments, the Subcommittee recommends a comprehensive financing strategy that combines a number of public and private financing components requiring coordination. Durable medical equipment needs should be considered along with traditional health and social services for this population. Components of a coordinated financing strategy are:

1. The Federal Government should create a Medicare, Part C program which would cover specified long term care services, both institutional and non-institutional:
 - A. Funding for this program could come out of general revenues, premiums, copayments, payroll tax, or a combination of some or all.
 - B. State Medicaid agencies would have the option of "buying in" to the Medicare program by paying a Part C premium for low income elders.

- C. Part C could be offered on a means tested or a sliding fee basis so as to be most accessible for those that require assistance.

As a first step in a strategy to implement this recommendation, the Massachusetts Congressional Delegation should be asked to introduce legislation directing the Secretary of the Department of Health and Human Services to establish a Blue Ribbon Commission charged with developing a concrete Medicare reform plan within a specified period of time.

- 2. Private long term care insurance should be developed as a major component of long term care financing to provide choice to those who can afford it and who may not want to rely on public programs or who want to purchase more flexible coverage;
 - A. Public sector incentives should be developed to encourage private sector initiatives in the short term.
 - 1. Regulatory changes may have to be made by the Division of Insurance to encourage insurance companies to enter the market. For example, strict regulation such as that for Medigap policies or minimum loss ratios may impede development or slow private sector entry. Regulatory flexibility is needed to foster the development of new, innovative products. In addition, policies would have to be rated in an actuarially sound manner to prevent cost shifting to the private sector.
 - 2. A State Commission to study the level of need for private long term care insurance, barriers blocking the development of such insurance, and strategies to encourage the development of such insurance should be established as proposed by House Bill 93.
 - B. Further study must be made by the State of the impact of a pro-competition vs. a mandated benefit approach.
- 3. A comprehensive financing strategy should encompass changes in tax policy, including credits to families supporting a family member with Alzheimer's Disease, in order to alleviate the burden on families. Mechanisms for protecting family assets should also be developed;
 - A. Tax credits could be used to encourage the purchase of private long term care insurance.
 - B. Tax credits could be designed in such a way as to provide an incentive for families to provide as much informal support to the Alzheimer's patient as possible.

- C. State agencies and the legislature should begin work on State level tax policy reform. The bills filed during this session which the Subcommittee feels have potential to provide relief to families caring for Alzheimer's patients are: H.3037; S.508; H.718; H.2500; H.2865; H.3954; H.2103; H.3032; H.4369; H.3785; S.85; S.511; H.1917; H.1287; H.503.
- D. Massachusetts' members of Congress should be more thoroughly informed of the financial impoverishment imposed on their constituents who are caring for dependents with Alzheimer's Disease. Further, they should be encouraged to support the passage of legislation to relieve this burden.
 - 1. Several current bills would reform tax policy to assist families in financing care of chronically disabled, including those suffering from Alzheimer's Disease. These could be first steps in national tax policy to address the needs of Alzheimer's patients and their families.
 - 2. The bills are: S.778, S.779, H.R.467, H.R.468, H.R.644, H.R.723 (See Appendix for further description of these bills.)
- 4. Adjustments to current reimbursement schedules to take into account the special care needs of patients with Alzheimer's Disease and related disorders need to be considered.
 - 1. The Rate Setting Commission, the Department of Public Health, and Medicaid should be directed to work together to establish a consistent policy to address this issue for nursing homes and adult day health programs.
 - 2. Medicare, Blue Shield and other insurers should also be directed to study this issue as it relates to physician reimbursement.
- 5. The feasibility of financing strategies that are geographic in nature with a fixed budget or capitated financing should be explored through state sponsored demonstrations.
 - A. Models that combine delivery of care and capitated financing could be tested as a possible means for getting both quality care and cost effective treatment.
 - B. Private foundations could be encouraged to donate funds for the initial development of such centers with government retaining responsibility for the cost of direct services.
 - C. A single State agency should be responsible for coordination and implementation of a managed care program, including applying for waiver of state and federal regulations.

D. On the federal level, Senate Bill 788, "Senior Citizens Independent Community Care Ac," should be acted upon favorably by the Senate Committee on Finance. This bill calls for the development of long term care demonstration projects in four states using the prepaid capitation model for providing a continuum of acute and long term care services to elders. Services provided in the demonstration program would include those currently covered by Medicare Part A and B plus: homemaker-home health aide services, adult care, respite care and service coordination.

Additional Recommendations

1. There is a growing need to educate elders, their families and the general population on the scope and limits of existing insurance coverage (Medicare, Medicaid, Medigap, and Private) for long term care.
 - A. State regulation of insurance policy statements that would require a standard format making benefit comparisons easily understandable.
 - B. Use of media campaigns that would touch large populations and stimulate discussion. The Division of Insurance could develop buying guides for consumers.
 - C. Government programs could be sponsored to raise the consciousness of elders as to the scope and limits of their insurance coverage. For example, the State would expand resources to develop and enhance education programs such as the MASSACHUSETTS ELDER ADVOCATES and THE SHINE (Serving Health Information Needs of Elders) programs.
 - D. ADRDA and other advocacy groups could include this area as an aspect of their public information activities.
2. Literature on financial issues should be made available to families of Alzheimer's patients soon after diagnosis to avoid unnecessary impoverishment of families.
3. There should be a longer period of retroactive determination of disability caused by Alzheimer's Disease by the Social Security Administration. This would enable an individual who lost a job due to the impact of the disease prior to diagnosis to collect disability payments if a diagnosis was made in a later stage of the disease.
4. In addition to financing reform for services to Alzheimer's patients and other elders needing chronic care, and to options for financial relief for families funding should be provided in increasing amounts for research into alternative cost-effective and care efficient models for the diagnosis and management of patients with dementing illness.

A. BROAD VS. CATEGORICAL APPROACHES
TO FINANCING AND DELIVERING
SERVICES TO THE ELDERLY

Recognition of cognitive impairment as a common problem among the elderly predates modern health and long term care policy. However, a number of scientific advances, as well as an emerging public awareness about Alzheimer's Disease and related disorders have brought the plight of cognitively impaired elders into sharp public focus. In an effort to address the problems of such patients and their families, there is the temptation to develop programmatic responses which are specific to the Alzheimer's patient and which limit eligibility to only those persons suffering from the disorder. It is our premise that such a narrow, categorical approach performs a disservice, not only to other elders in need of long term care services, but to the Alzheimer's patient himself.

A crisis situation exists for all elders who require long term services because of chronic disorders. To address only one such condition will further fragment the system and exacerbate the current level of competition among providers of service. A coordinated approach which considers functional capacity and need for service regardless of specific diagnosis is more likely to improve quality of life for more people while avoiding many of the negative consequences of disease specific categorical programs.

A Changing Context for Public Policy and the Cognitively Impaired

Judging from the explosion of articles in the popular areas, one would think that Alzheimer's Disease had only recently been discovered. This is not the case; the first case description was published in 1907 (Alzheimer, 1907). However, the application of the diagnosis of Alzheimer's disease (senile dementia of the Alzheimer's type) to the elderly is a more recent development. Prior to this, such cases were more likely to be called chronic brain syndrome, hardening of the arteries, or senility. By any name, the disease was devastating to the patient, his family and other caretakers.

Prevalence of Alzheimer's disease increases with age. Therefore, increasing numbers of elders in the population will result in larger numbers of Alzheimer's patients. Furthermore, until recent decades, patients of the disease had decreased life expectancies and usually died with relatively short periods of total dependency. However, a dramatic shift in this trend has resulted in prolonged periods of dependence for patients and has increased the prevalence of the disease. A ground-breaking study by Essen-Moller and colleagues in southern Sweden followed a population of 2500 individuals carefully screened for mental disorders in 1947 and rescreened in 1957 and 1967 (Essen-Moller, et al., 1956; Gruenberg, et al., 1976). In 1947 there were 24 people in the study who were over the age of 60 with senile dementia, all of whom were dead by the next screening in 1957. But of the 48 cases discovered in 1957, the survivorship over the next decade resembled that of the general over 60 population. For women, the prevalence rate rose from 3.2 to 5.7% between the two decades, and for men the rise was

from 2.3 to 4.9%. The average duration of the episode of illness had at least doubled in that one decade. Today, individuals suffering from dementing disease in old age are not surviving longer because of new treatments for dementia, but rather because of improved medical care for other diseases and symptoms.

This increase in life expectancy and therefore prevalence of the disorder places increased strain on family care providers and public institutions charged with the care of such patients. Not only are there increased numbers of individuals requiring care, patients are surviving longer into the illness, experiencing greater loss of function, and requiring a much more intensive level of care. Public policy aimed at containing spiraling costs of health care and the deinstitutionalization of patients from mental hospitals have converged to place even greater demands on community-based and institutionally-based long term care. Public funding of such programs is means tested, requiring "spend-down" of personal resources to qualify for assistance. The heaviest burden of care falls to family members.

Why then should we not provide categorical programs for the Alzheimer's patient?

Risks for Categorical Programs for the Alzheimer Patient

There are a number of risks associated with the implementation of categorical programs restricted to Alzheimer's patient. A number of these risks are related to the problem of accurate diagnosis of the condition. Thus far, no definitive diagnostic procedure has proven accurate for general practice. The current diagnosis is an exclusionary process in which all other potential causes for the observed symptoms are tested for and excluded. At the present time, only an autopsy confirms the diagnosis of Alzheimer's. The first potential risk of a categorical program is that a patient will be more likely to be misdiagnosed as having Alzheimer's Disease, when he/she is actually suffering from a reversible dementia. The added incentive of eligibility for special services for the Alzheimer's patient may serve as a disincentive to a full work-up of dementia symptoms. This, in essence, becomes a self-fulfilling prophecy, in that untreated reversible dementia usually becomes permanent, a terrible tragedy.

A second risk of categorical programs based on such a non-definitive diagnosis of Alzheimer's disease is that there will be incentives to label any patient requiring long term services as being an Alzheimer's patient. The sorts of services required by the Alzheimer patient and his family are not specific to the disease. Many elders suffering chronic conditions require similar services, and the well meaning caretaker may find himself under considerable pressure to diagnose Alzheimer's disease in order to qualify the patient for needed services, particularly in light of somewhat vague diagnostic criteria. This may lead to a number of unintended consequences. First, the stigma of such a diagnosis may be transferred along with the positive aspects of qualifying for services. Because an Alzheimer's patient is expected to have decrements in cognitive function, new symptoms of cognitive impairment in an improperly diagnosed patient may not be treated or the patient may develop learned helplessness because of decreased demands. Finally, the diagnosis of Alzheimer's will lose meaning because of the large array of patients thus diagnosed.

Stigmatization of the patient is another potential risk of categorical programs. The diagnosis of a dementing illness carries with it important personal and social consequences. Subtle distinctions of competency are frequently lost once a label of "dementia" has been attached. Under a categorical program, incentives would exist for early diagnosis and labeling. Yet, early in the disease, the patient may well be able to participate in important decisions regarding his care, treatment and financial matters. The capacity to make such decisions may be called into question, given the application of the label "Alzheimer's."

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B. MEDICARE REFORM

Financing of services is a central issue in the care of the Alzheimer's patient. Contrary to popular belief and the expectation of many elders, much of the care required by chronically impaired elders is not covered by any form of private insurance or public funding. Medicaid reimburses some long term care services, but only for individuals meeting stringent eligibility requirements related to income and assets. As a result, many elders and their spouses become impoverished before any public program steps in to provide assistance. Entry of private insurers into the long term care market has been slow and would require relatively broad enrollment in order to provide a long term care benefit at reasonable prices.

In response to the clear need for improved coverage of long term care services, policy makers have begun to consider reforms in the Medicare Program to address this problem. Three such options provide models for consideration. These are: 1) expanded coverage of the medical aspects of long term care, 2) a categorical "Alzheimer's benefit" and 3) coverage of long term care including selected social services as a new Part C to Medicare.

Current Medicare benefits are provided through two programs, Part A - Hospital Insurance and Part B - Physician services. The major emphasis of the Medicare Program has been on medical services for relatively acute conditions. Payment for home health, institutional care, or durable medical equipment is limited for the most part to short term rehabilitation or terminal care. There is limited reimbursement for physician visits to nursing homes.

One option under consideration is to expand the definition of health services reimbursable under Medicare. This would allow for a separation of aspects of long term care which are "health" services from those which are "maintenance" related such as room, board, and personal expenses. Under such an option, a nursing home resident would have Medicare coverage of medical, nursing, medications and special therapies paid for by Medicare regardless of income or assets. Medicaid payments would be limited to "maintenance" costs and would be provided only to those patients meeting income eligibility requirements. Such a model would protect elders and their families from the full cost burden, requiring individual payment only for those services that one might otherwise expect to pay (housing, food, personal costs). However, consideration should be given to the need of the spouse of an institutional person to also maintain a household. Further, this option may not prove to be cost effective. It may be bureaucratically complex and have a tendency to encourage agencies and care facilities to shift costs from the "maintenance" side to the "health" side of the ledger. Further, such a program might provide perverse incentives to over "medicalize" care and to provide more "health" services than required by the client.

A special categorical Alzheimer's benefit under Medicare has also been suggested. Under this option, individuals diagnosed as Alzheimer patients would be eligible for a broad array of specialized health and social services paid for by Medicare. The problems associated with categorical programs of this sort are discussed in more detail in another section of this report. Lack of a procedure for definitive diagnosis for Alzheimer disease limits the implementation of such an option. Furthermore, the experience of the runaway costs of a similar program for End Stage Renal Disease leaves policy makers wary of such an approach.

A third option under consideration is the implementation of a Part C to Medicare to cover long term care services. Such an approach could have several advantages. First, if it involves a mandatory premium, risk could be spread over a broad population. Second, this option would allow for a mix of income sources for the program including premiums, general revenues and payroll taxes. Third, Medicare is an administratively efficient program, thus maximizing the amount of program income flowing to direct services. Under such an option, states might choose to pay Part C premiums for low income elders just as many now pay for part B.

There are important issues to be addressed regarding this option. What will be the distribution of income for the program among premiums, copayments, payroll taxes and general revenue? Will a sliding scale be used to determine either premiums or copayments? Will payments for care be in the form of vouchers or will care be directly reimbursed? How will quality of care be regulated and ensured? Finally, what process will be used to assess and certify need for care? Implementation of this option is a complex process and the major responsibility falls to federal rather than state policy makers. Nonetheless, advocacy from state and local planners and policy makers may encourage programmatic action in this area.

C. PRIVATE LONG TERM CARE INSURANCE

Background

Private long term care insurance is emerging as an innovative approach to the financing of nursing home and home care services for chronically ill and disabled elders. Such insurance products are on the frontier of increased private participation in the private-public partnership in long term care financing. As government cutbacks continue to expand and costs continue to rise it is likely that more interest in private insurance policies will emerge.

These policies often serve as supplements to Medicare and as buffers against Medicaid's spend-down requirements for eligibility. While many private insurance products are being developed, private participation in the long term care market is currently quite small.

Meiners (1984) points out that only 1% of the 24.2 billion dollars spent on nursing home care was covered by private insurance policies whereas 43% of nursing home expenses were paid directly by families often at great financial hardship.

The increasing income of the elderly is contributing to making the market more appealing to private insurers. Approximately 1/3 of elders age 55-65 have financial security and equity available. A 1980 study showed that 27% of all elders (65+) could afford long term care insurance costing 450 \$/year. Additionally, 47% of elders ages 65-69 could afford it, but only 9% of elder age 75+ could. In the past, only 34% of elders had employer pensions. Now, 50% have them and in the year 2000, 80% of elders will have pensions. Other factors which will improve elders ability to pay for private insurance are higher earnings, better SSI benefits and the fact that people will continue working until they are older. By 1990, it is estimated that 65% of persons age 65-69 will be able to afford long term care insurance (Kennel, 1984).

Several commercial insurance companies are offering limited liability nursing home programs. These commercial policies feature strong medical underwriting, benefit limitations and prescribed access channels. Many of these policies appear to be quite comprehensive at first glance, but upon closer inspection their limitations become clear. The contribution by these policies may be limited due to the fact that many avoid home health benefits that, while extremely important, are costly or difficult to manage.

Issue

While the development of insurance programs to provide these benefits is desirable, the costs and potential problems require a very careful approach. Several issues must be considered before private insurance can play a meaningful role in the financing of such care. One of the most important issues is that of voluntary participation by private insurers as opposed to a mandated benefit approach. Listed below are some of the advantages and disadvantages of both approaches. However, since no state has actually implemented a mandated benefit approach to long term care insurance and since few insurers have ventured forth with innovative products, the Subcommittee feels there is insufficient data on which to recommend one approach over the other. It is recommended, however, that while the state further explores this threshold question, that immediate incentives be developed to encourage private insurers in Massachusetts to enter this market.

Recommendations

- 1) Further study of impact of free enterprise competition versus mandated benefits.
- 2) Public incentives to encourage private sector initiatives.

Advantages

1. A voluntary approach to private long term care insurance would stress cooperation among payors and reduce cost shifting. Both public and private insurance programs could assume part of the responsibility for coverage and thereby reduce the burden on any one payor.
2. Voluntary insurance offerings would provide coverage for families who could afford to purchase private policies, while allowing public programs to provide for low income families.
3. A voluntary approach will foster the kind of competition that engenders the development of a wide variety of models. These models will attempt to take advantage of innovations in the delivery of services as well as new financing ideas.
4. A voluntary private insurance approach represents a long range solution in which insurance companies sell policies that are actuarially sound. In light of the increasing number of elderly individuals, this is a more stable approach to the financing of a growing service need, whereas a mandated benefit could stretch existing private insurance policies beyond the limits of fiscal soundness.
5. Development of long term care insurance products that are actuarially sound and marketable to current elder populations have been shown by several recent studies (Mieners 1984 , Friedman 1984) to be feasible.

Disadvantages

1. The current regulatory environment is not conducive to development of long term care products. Government incentives may be necessary to encourage private sector initiatives such as exemption from regulation which may lead to significant losses for private insurers as well as legislative and regulatory changes to Medicare and Medicaid to avoid cost shifting from public to private sector.
2. The timing of initial private long term care insurance offerings may not be as soon as policies offered under a mandated approach. While the insurance industry is moving toward the development of private long term care policies, considerable development work and research would have to be completed before they could be offered.
3. The benefits provided in an initial private insurance offering may not cover the kind or amount of long term care services as those that may be required under law in a mandated benefit.
4. Private insurance policies for long term care may have to be more expensive than a mandated policy depending on the size of the resulting risk pool. If the private policies are offered at a higher premium, they may be less available to low and moderate income elders.

Advantages

6. A mandated approach to private insurance involvement will inevitably lead to long legal battles and minimal insurance offerings. Further, such an approach may create a sufficiently difficult environment so as to render more cooperative solutions between the public and private sector less feasible. An example of such a situation is mandated mental health benefits which are currently being debated by the Supreme Court.
7. Mandated approaches may encounter stiff opposition from members of the business community and business coalitions seeking to contain the increasing cost of employee benefits.

Disadvantages

- 1 Meiners, Mark R., and Tave, Arlene K., "Consumer Interest in Long Term Care Insurance: A Summary of the Elderly in Six States", unpublished paper available from National Center for Health Services Research, December, 1984.
- 2 Friedman, B. et al., Medicare Beneficiary Decision Making About Health Insurance: Implications For A Voucher System' unpublished paper available from Center for Health Services and Policy Research, October 1984.

Advantages

1. Long term care policies would be offered within a definite time frame as specified by law. This is in contrast to voluntary private insurance which may not become as quickly available.
2. A private insurance mandate could allow for the spreading of risk over a much larger risk pool than would otherwise be possible. The broad spreading of risk would potentially lower the price of private policies.

Disadvantages

1. Mandated private insurance policies for long term care would most likely be very minimal in nature providing only those benefits specified by law. Insurers would devote considerable resources to fighting the mandate and less resources to developing new approaches.
2. Mandated benefits are opposed by private insurers. Frequently, such mandates do not lead to programs that are in the best interest of the consumer. An example of such a situation is mandated mental health benefits which are currently being debated in the Supreme Court.
3. The business community would be against any such mandate because of its impact on the increasing cost of health benefits for which employers are responsible. Business coalitions would join other opponents attempting to prevent passage of the mandate.
4. Opposition by both business and private insurers would create a negative environment which could prevent all parties from working together to develop a more creative long range solution.
5. A mandated private insurance long term care approach could encourage large employer groups to bypass the mandate by self-insuring as has been the case with other mandated benefits such as mental health. A growth in this trend would make long term care insurance less accessible to individuals covered by group insurance and reduce the risk pool over which the cost could be spread.
6. Mandated long term care benefits could add a significant amount to the premium of existing policies such that health insurance policies may become less affordable for many employees, non-group purchasers and Medex subscribers.

(Cont'd)

Advantages

Disadvantages

7. Mandated approaches often result in a benefit package that is almost uniform across the various insurance policies. Companies faced with a mandate are not likely to devote additional resources to develop more innovative products but are likely to offer only the required benefit. This approach will impede the development and implementation of new service delivery ideas and funding mechanisms as has been the case for mental health benefits.
8. Mandated private long term care policies may be viewed as providing coverage for all in need thereby discouraging Medicare reform or changes in Medicaid's "spend down" policy.
9. Mandated benefits represent a quick short term solution which assumes that one payor, private insurance, can marshal the resources necessary to provide comprehensive coverage. The magnitude of the need for long term care services is such that no single payor will be able to meet the needs of an expanding elderly population. The limits created by such a short term solution may make longer range all-payor solutions less feasible.

D. TAX POLICY FOR FAMILIES

Background

Under current arrangements, public policy is unclear regarding the societal question of the appropriate balance between public support for services needed to care for Alzheimer's patients and others requiring long term care versus the responsibility of individual elders and their families. At the same time, it is unlikely that any one payor will be willing or able to accept full responsibility for financing long term care. Unfortunately, the burden of care for the Alzheimer's patient often falls disproportionately on individuals and their families. Although the societal question of how responsibility for care should be shared by the public (federal and state governments) and private sectors (private insurers, individuals and families) remains to be answered, there is an immediate need to alleviate the burden that is borne by families. Changes in federal and state tax policy can address some of the pressing financial strains faced by families while at the same time becoming one part of an overall comprehensive financing strategy.

Options

There are two principal tax mechanisms for families caring for an elderly relative at home. The first mechanism is a standard deduction or exemption for taxpayers who have an elderly relative residing in their household, and who provide more than one-half of the support for that elderly relative. The second mechanism for supporting families caring for an elderly relative is to tie the tax credit to the income used for care. This frees the taxpayer to produce, analogous to and actually added to current child care tax credits.

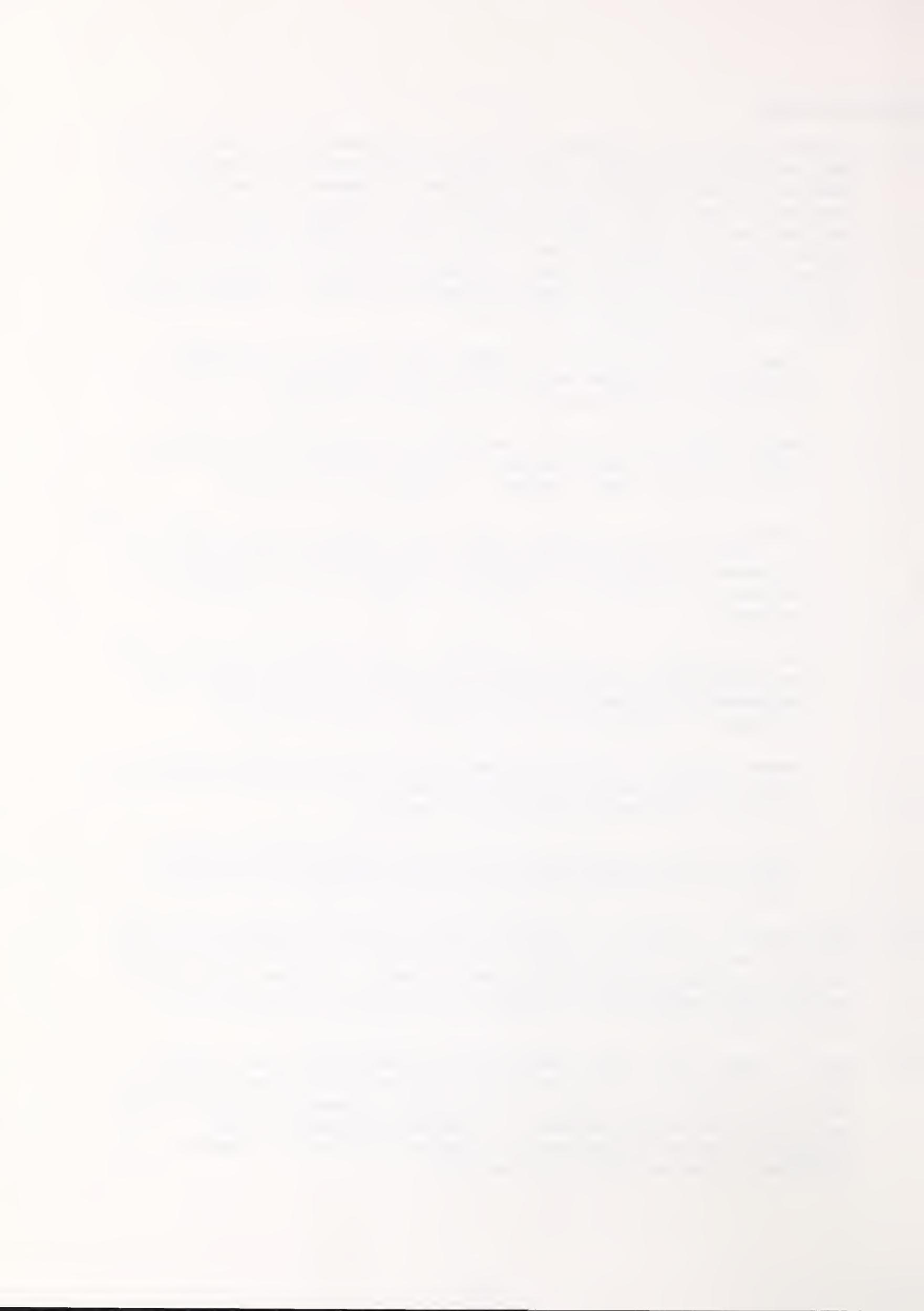
Two federal bills have been introduced to provide a standard deduction: House 467 by Olympia Snow (R-Maine) and Senate 263 by Metzenbaum (D-Ohio). The second bill is Alzheimer's specific.

In Massachusetts, numerous bills have been filed in this category. By the date of the final commission report many of these will undoubtedly be combined Bills providing for an income tax credit for families caring for their elderly relative. These include: House 718, 2103, 2500, 2865, 3032, 3037, 3785, 3954 and 4369, and Senate 508. Bills providing for a tax exemption include: House 85, 503, 1272, 1287, 1917, 1941 and Senate 511.

The only bill now pending utilizing a tax credit for costs related to the care of elders is Federal House Bill 468, also introduced by Olympia Snow. This requires that the family actually pay for the home or day care of the relative.

Recommendations

- 1) Currently there are a number of federal and Massachusetts Bills which have been introduced which would recognize and provide incentives for families caring for persons with Alzheimer's Disease and Related Disorders. Those bills which this committee feels have special merit for State support are: H.3037, S.508, H.718, H.2500, H.2865, H.3954, H.2103, H.3032, H.4369, H.3785, S.85, S.511, H.1917, H.1287, H.503. Federal bills which would reform national tax policy to assist families in financing the care of chronically disabled elders, including those suffering from Alzheimer's disease are:
 - Senate Bill 778. A bill to amend Title XVIII of the Social Security Act to allow Medicare coverage for home health services provided on a daily basis. (Committee on Finance)
 - Senate Bill 779. A bill to amend the Internal Revenue Code of 1954 to allow a credit against tax for expenses incurred in the care of elderly family members. (Committee on Finance)
 - House Bill 467. A bill to amend the Internal Revenue code of 1954 to allow the dependent care credit for expenses with respect to dependents incapable of self-care without regard to whether such expenses are incurred to enable the taxpayer to be gainfully employed.
 - House Bill 468. A bill to provide a deduction from gross income for individual taxpayers who maintain home care and adult care expenses of a dependent of the taxpayer who suffers from Alzheimer's Disease or related organic brain disorders.
 - House Bill 644. A bill to amend the Internal Revenue Code of 1954 to allow a credit against income tax for expenses incurred in the care of certain elderly family members.
 - House Bill 723. A bill to amend the Internal Revenue Code of 1954 to allow a deduction for the cost of medically necessary custodial care provided to elderly individuals.
- 2) Massachusetts' members of Congress should be more thoroughly informed of the financial impoverishment imposed on their constituents who are caring for dependents with Alzheimer's Disease. Further, they should be vigorously encouraged to support the passage of legislation to relieve this burden.
- 3) Most of these bills allow exemptions or deductions for any elderly relative, regardless of health or care needs, usually specifying that the relative must be at least 75 years old. These bills might better serve the above stated purposes if they were amended so that eligibility is based upon age or a diagnosis of senile dementia of the Alzheimer's type or a related disorder.



- 4) Many of these bills also require that the relative provide more than one-half of the support of the family member. Amendments might be considered to allow the relative to make an exemption for the legitimate costs of care regardless of the percentage of support.

E. GEOGRAPHIC MANAGED CARE FOR PATIENTS IN NEED OF CHRONIC CARE

Background

As health care costs escalate, the health delivery system has been changing so as to make the most efficient use of health care resources. One of the most effective changes in the health care delivery system has been the advent of geographically specific, managed care plans that combine the financing and delivery of services. These plans operate under a fixed budget, employ a wide variety of services so as to select the care that is the most appropriate and least costly, and put providers at risk. The most common of these types of plans are HMOs. While long term care is not usually covered by HMOs, a federal demonstration project known as the Social Health Maintenance Organization is testing an expanded benefit package which includes limited long term care. The purpose of these demonstrations is to test a fixed budget delivery system with expanded services for individuals with widely divergent levels of impairment. The HMO and the SHMO demonstrations may serve as models for development of Alzheimers' programs which stress cost effective and innovative service delivery at the most appropriate level.

Issues

While the managed care type concept could be invaluable in treating long term care patients, several issues exist as to how such concepts would be applied to long term care. Some of these issues are as follows:

- A determination would have to be made as to the definition of when an Alzheimer's patient is in need of services, and what course of treatment would be best. The current variation in both of these areas could make a single approach difficult to implement;
- Funding sources would need to be combined from a wide variety of payors who currently do not cover Alzheimer's Disease. Individual payors would have to agree to allow their funds to be used in a manner that may not provide them as much control as they are accustomed;
- The system would have to be designed in such a way as to support rather than supplant informal supports. This can become difficult in a model that attempts to provide for a wide variety of needs.



Options

A limited demonstration would allow the opportunity to test a wide variety of approaches toward funding and service delivery. There are several options for how such a demonstration could be implemented.

- A State agency could apply for Medicare and Medicaid waivers, as well as take responsibility for coordination and implementation of a managed care program.
- Private foundations could be encouraged to provide seed money to establish a long term managed care program with government resources paying only for direct services.

F. THE NEED FOR BENEFITS EDUCATION

Background

The need to educate the elderly and their families about their health insurance is becoming apparent. Two recent studies (Meiners, Friedman, et al.) focused on how well Medicare enrollees understand their long term care benefits. Each of these studies reveal a level of misunderstanding that is quite astounding. In both studies focus groups were used to elicit attitudes and test knowledge of long term care. One of the most common misunderstandings was the notion that Medicare would cover nursing home stays for other than skilled nursing. In addition, there was great misunderstanding about how much it would cost to pay for nursing home and home health services on a private paying basis.

The lack of knowledge about long term care can be attributed to several factors. One obstacle in gaining an understanding of long term care is the terminology. The differences between skilled nursing, intermediate care, and rest home care are not immediately apparent, and may vary according to setting or provider. Many payors use different definitions of common terms making it very difficult to understand which things are covered by insurance.

A second is related to individuals' perception of their own need for long term care generally and Alzheimer's coverage specifically. Many elders do not foresee needing a nursing home stay. A large portion of the elders interviewed preferred to think that they will be cared for by their children or that they will die before they need such care. Third, lack of systematic description of benefits from any single source contributes to misunderstandings about long term care coverage.

Issues

This lack of understanding may lead to several obstacles for new approaches to the financing of long term care.

- Many elders show little interest in LTC products because they believe they are already covered by Medicare. Those who realize the limitations of their coverage are frequently already in need of LTC insurance.
- Those who do feel the need to purchase some additional form of insurance may do so without really understanding what it is that they have purchased. Some of the commercial products on the market may appear to offer coverage for nursing home care, yet the purchaser may not be able to understand the limitations of a given policy. Strict definitions of care and access limits can render these policies almost impossible to utilize.

- Private insurance products that include substantial benefits will have to be priced higher, yet the significance of the difference in benefits may not be appreciated. This lack of understanding may lead purchasers to select policies on the basis of what they think the product should cost and not on what it provides.
- As of yet, elders have not been strong advocates for better alternatives for financing long term care. Many elderly groups have begun to work on this issue, but in general the lack of a good long term care insurance system is not stated by elders as one of their major concerns.

Options

Several options exist as to how to approach the education for elders and their families about health insurance, and long term care insurance in particular.

- State regulation of insurance policy statements that would require a standard format making benefit comparisons easily understandable.
- Use of media campaigns that would touch large populations and stimulate discussion. The Division of Insurance could develop buying guides for consumers.
- Expansion of state resources to develop and/or enhance education programs such as the MASSACHUSETTS ELDER ADVOCATES Program and the Serving Health Information Needs of Elders (SHINE) Program. (SHINE will pay stipends to trained health counselors.)

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